La salud mental en la discapacidad intelectual. Un recorrido de interrelaciones

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Índice

Ocho años para hacer esta tesis. Ocho años no sólo de investigación, sino de práctica en la atención a la discapacidad intelectual, de visitas a otros lugares del mundo en los que aprender, muchas personas conocidas, profesionales maravillosos, muchas personas con discapacidad que han contado historias, que han sido entrevistadas, muchas familias escuchadas…

Ocho años que resumir en un proyecto de tesis, y que, sin perder el foco del rigor científico, intente dejar vislumbrar el verdadero enriquecimiento personal que ha supuesto. Y desde luego, el valor práctico, pues si han sido ocho años ha sido también en parte porque cada problema científico encontrado en el camino hubiera sido la mitad de enriquecedor si hubiéramos desoído la implicación práctica que escondía. Comenzando con una beca FPU y acabando en el trabajo práctico de coordinar recursos de atención a la discapacidad. Grandes parones en el camino de redactar este proyecto, pero que son los que le dan sentido: la creación del centro de día DIEM al escuchar la problemática de la desatención de la salud mental de las personas con discapacidad intelectual o la puesta en marcha de la Unidad de Atención a Víctimas tras caer en la cuenta de la desprotección al abuso sexual de las personas con discapacidad intelectual. Parones también para escribir en revistas científicas lo que nos íbamos encontrando, o para presentaciones en congresos, o para escribir guías de utilidad para los profesionales de atención directa, o para impartir innumerables cursos de formación. Muchos parones que de nuevo dan cuenta de estos ocho años, pero que, como decíamos al comienzo, son los que han dado valor a este proyecto tesis.

Esperemos que al menos Kurt Lewin, estuviera orgulloso de nosotros, porque si algo tiene esta tesis, es la puesta en práctica del término investigación – acción, enlazando el enfoque experimental de la ciencia social con programas de acción social que respondan a los problemas sociales principales. *Mediante la investigación–acción se pretende tratar de forma simultánea conocimientos y cambios sociales, de manera que se unan la teoría y la práctica*[1] . Creemos que eso, al menos, aunque sea un poquito, lo hemos conseguido.

[1] *Lewin, Kurt (1946): Action research and minority problems; Journal of Social Issues 2 (4): 34-46.*

Agradecimientos institucionales

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Eight years with this work. Eight years not only researching, but applying the knowledge found to practical work in intellectual disability. Visiting other countries where lots to learn, meeting excellent professionals, many people with intellectual disability sharing stories, many families heard…

Eight years to synthesise in this doctoral project, and which, without losing a scientific approach, should show the real personal enrichment they have brought along. And moreover, the applicable and practical value they have also generated. It has been eight years time because each scientific dilemma we have found would not have been as enriching if we had overheard its practical implications.

Starting with the Ministry of Education's scholarship and ending with the coordination of the disability resources at the Fundación Carmen Pardo-Valcarce. And these practical implications are the ones which give the global and real meaning to this work: the creation of the DIEM day Centre (first service in Madrid to attend the mental health problems of people with intellectual disability)or the development of the "Victims of Abuse Unit" after listening to the vulnerability of people with intellectual disability to sexual abuse. Papers, congresses, writing guides for professionals and caregivers, teaching…
We hope that at least Kurt Lewin would be proud of our work, because the term action-research has been truly applied, building bridges between social sciences and social interventions. "Various forms of social action and research leading to social action". Eight years with this work. Eight years not only researching, but applying the knowledge found to practical work in intellectual disability. Visiting other countries where lots to learn, meeting excellent professionals, many people with intellectual disability sharing stories, many families heard…

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1. La discapacidad intelectual.

Pese a que la presente tesis pretende abordar el fenómeno de la discapacidad intelectual, sería llevarnos a engaño el no partir de que se trata de un grupo difuso y difícil de delimitar dado lo escurridizo del concepto.

La discapacidad intelectual (DI) es un constructo que incluye un amplio rango de condiciones derivadas de las acción de diversos factores biológicos, psicológicos o sociales (Salvador & Bertelli, 2008). Tanto la terminología y la definición como la clasificación empleadas para referirse a este concepto son heterogéneas. En el pasado se han utilizado los términos "subnormalidad", "deficiencia mental" y "retraso mental" (que se empapan de connotaciones negativas y deben evolucionar más rápido que lo que tardan en convertirse en un insulto de uso común) aunque en la actualidad hay un amplio consenso en el empleo del término "discapacidad intelectual", que ha evolucionado hacia "personas con discapacidad intelectual y del desarrollo".

No existe ninguna otra condición en la medicina que reúna las especificidades y los matices que rodean al concepto de discapacidad intelectual. A pesar de ser una condición con una prevalencia de entre el 1,5%, en países occidentales, al 4%, en países en vías de desarrollo (Durkin, 2002), ha recibido muy poca atención por parte de la medicina y de los servicios sanitarios en general. De hecho, en la mayoría de los países es relegada al ámbito de los servicios sociales, y ni siquiera fue incluida en el estudio de la Carga Global de Enfermedades del Banco Mundial (Murray y López, 1996).

Un factor que incrementa la dificultad de comprensión del término de la discapacidad intelectual es el marco conceptual de referencia. Según la AAIDD (American Asociation on Intellectual and Developmental Disabilities), no es un trastorno médico, aunque sea codificado en una clasificación de enfermedades (CIE-10) –actualmente en revisión para la décimo primera versión y donde esperamos nuevos e importantes avances en la conceptualización de la discapacidad intelectual-. Tampoco es un trastorno mental, aunque se recoja en clasificaciones de trastornos mentales (DSM- IV-TR). La discapacidad intelectual, como sugiere la AAIDD (2010), se refiere a un estado particular de funcionamiento intelectual y adaptativo, que se inicia en la infancia y en el que las limitaciones de la inteligencia coexisten con limitaciones asociadas en habilidades conceptuales, sociales y prácticas. Más allá, el concepto de discapacidad intelectual describe el ajuste entre las capacidades del individuo y la estructura y las expectativas del entorno personal y social del sujeto.

Los problemas y déficits en un sujeto con discapacidad intelectual puede tener una etiología específica, pero discapacidad intelectual no es sinónimo de etiología. Vemos, pues, que el concepto es dual, implicando

a la vez un déficit en el individuo y un déficit adaptativo-funcional relacionado con el entorno cultural. Ambos conceptos son mutuamente dependientes y válidos, recogiendo así el marco de la OMS reflejado en la CIF, que desarrollaremos más adelante, y que sitúa la discapacidad a caballo entre la persona y su entorno, no encontrándose ni en uno ni en otro (ni la sociedad, como dirían los postulados de Hahn y el modelo social, ni en el individuo, como apuntarían los modelos médico-biológicos).

Retomando la actual definición de la AAIDD, el término de discapacidad intelectual incluye necesariamente tres componentes esenciales:

- funcionamiento intelectual significativamente inferior al promedio,

- marcado déficit en la capacidad del individuo para adaptarse a las demandas diarias del entorno social (ninguno de estos aspectos -baja inteligencia y conducta adaptativa deficitaria- resultan suficientes para el diagnóstico de discapacidad intelectual tomados aisladamente).

- y edad de inicio inferior a los 18 años.

Pese a que estos tres criterios delimitan un triángulo en el que enmarcar a un grupo de la población, de nuevo los lados de este triángulo son escurridizos. Las dos primeras premisas aluden a limitaciones significativas y por lo tanto, a estadística.

Hasta la décima edición de la AAIDD, se consideraba un CI por debajo 70 como el punto de corte. Si bien el número de 70 se ha ido maquillando en las sucesivas ediciones, sustituyéndose por limitaciones significativas a juicio de expertos para evitar el excesivo peso de los tests de inteligencia, la realidad subyacente es que se trata de un criterio de comparación. Sean dos desviaciones típicas por debajo de la media (CI de 70, X= 100; DT=15), o lo que es lo mismo, el 2,5% de la población si atendemos a la desigualdad de Chebichev, o bien sean limitaciones significativas a juicio de un experto, lo que encierra es que el punto de corte lo define “lo habitual”, “la norma” y no nada en sí mismo (ver figura 1). Es un punto de corte aleatorio en un continuo, con el que dividimos a la población entre “discapacitada intelectual” y “normal”. Y por ende lo mismo es aplicable al criterio de limitaciones significativas en las habilidades adapatativas. Para más *inri*, ambas aluden a conceptos como inteligencia y habilidades adaptativas. Tratar ambos aquí sería una tesis en sí misma, por el escurridizo concepto de inteligencia (Martorell y Ayuso-Mateos, 2004) y por la asunción de la propia AAIDD de su imposibilidad de delimitar de qué hablamos cuando nos referimos a habilidades adaptativas, habiendo la AAIDD modificado los criterios en cada una de sus 11 ediciones de su definición de discapacidad intelectual, y no habiendo encontrado un sustento teórico que delimite de qué se componen las habilidades adaptativas (por ejemplo, un análisis factorial estadístico).

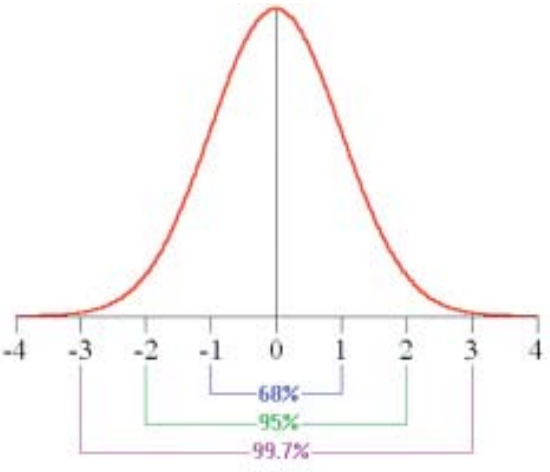

figura 1. Distribución porcentual según desviaciones típicas.

Con todo lo dicho, en la actualidad resulta erróneo considerar la discapacidad intelectual desde un punto de vista unidimensional. Por el contrario, ha de ser analizada como fenómeno multidimensional, lo que supone la interrelación de los aspectos fisiológicos, psicológicos, médicos, educativos y sociales de la actividad y la conducta humana (Leonardi et al., 2006). De hecho, la definición de discapacidad intelectual que hemos presentado anteriormente hay que matizarla con las siguientes premisas de la AAIDD:

1. Las limitaciones en el funcionamiento presente deben considerarse en el contexto de ambientes comunitarios típicos de los iguales en edad y cultura.

2. Una evaluación válida ha de tener en cuenta la diversidad cultural y lingüística, así como las diferencias en comunicación y en aspectos sensoriales, motores y conductuales.

3. En un individuo, las limitaciones coexisten con capacidades.

4. El objetivo fundamental de identificar las limitaciones en el funcionamiento de la persona es el de desarrollar un perfil de los apoyos necesarios.

5. Si se ofrecen los apoyos personalizados apropiados durante un periodo prolongado, el funcionamiento en la vida de la persona con discapacidad intelectual generalmente mejorará, por lo que no se puede considerar la discapacidad intelectual una condición estática, sino que varía en función de los apoyos que reciba la persona.

En resumen, el concepto no sólo es escurridizo, sino que aglutina a un grupo muy heterogéneo de personas, más si cabe que el de personas sin discapacidad intelectual como bien nos enseña la estadística (las distancias en los polos de la curva normal son infinitas, ya que la curva es asintótica).

1.1. Intellectual Disability: an approach from the health sciences perspective.

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Intellectual disability: an approach from the health sciences perspective

Luis Salvador-Carulla,[1] Carmen Rodríguez-Blázquez,[2] Almudena Martorell.[3]

Salvador-Carulla L, Rodríguez-Blázquez C, Martorell A. Intellectual disability: an approach from the health sciences perspective. Salud Publica Mex 2008;50 suppl 2:S142-S150.

Abstract

Intellectual disability (ID) is a complex condition that has not aroused very much interest in the health sciences and medical fields. As a result, a large part of the responsibility for caring for individuals with ID has fallen in the areas of education, social services and volunteering. Nevertheless, intellectual disability is a very significant health problem, whether because of its prevalence, the costs to the public health system, the families and society in general or due to related health complications. ID should be a priority area of study and action in the health field. This article reviews the conceptual, diagnostic and etiological problems that affect intellectual disability, as well as factors related with the health of the persons who are affected. In addition, some recommendations are outlined for improving health care for this population group.

Key words: intellectual disability; health; conceptual framework

Salvador-Carulla L, Rodríguez-Blázquez C, Martorell A. Discapacidad intelectual: un enfoque desde la perspectiva de las ciencias de la salud. Salud Publica Mex 2008;50 supl 2:S142-S150.

Resumen

La discapacidad intelectual (DI) es una condición compleja que no ha despertado gran interés en el campo médico y en el de las ciencias de la salud. Como consecuencia, gran parte de la responsabilidad del cuidado de los individuos con DI ha recaído en las áreas de la educación, el servicio social y el voluntariado. Sin embargo, la discapacidad intelectual es un problema de salud muy significativo, ya sea por su prevalencia, por los costos para el sistema de salud pública, para las familias y para la sociedad en general o debido a las complicaciones de salud relacionadas con ella. La DI debería ser un área de estudio y de acción prioritaria en el campo de la salud. Este artículo revisa los problemas conceptuales, diagnósticos y etiológicos que afectan a la discapacidad intelectual, así como los factores relacionados con la salud de las personas afectadas. Además se delinean algunas recomendaciones para mejorar el cuidado de la salud en este grupo de población.

Palabras clave: discapacidad intelectual; salud; marco conceptual

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Historically, intellectual disability (ID) has received variable attention in developed countries –from charity to the development of specific devices for social-educational care–.

ID terminology has varied over time. In the past, terms have been used such as "imbecility," "mongoloidism," "mental deficiency" and "mental retardation." Since 2004, there has been a broad consensus in favor of the use of the term "intellectual disability." Prominent international and national associations have already accepted the denomination of this disorder. Thus, the American Association of Mental Retardation (AAMR) has changed its name to the American Association of Intellectual Disability (AAIDD)[1] and the World Health Organization (WHO) uses this term as a synonym for mental retardation.

No other medical illness exists that brings together the specific characteristics and nuances entailed by the concept of ID, although it has received very little attention on the part of health sciences and health services in general. In fact, in many countries, caring for persons with ID has been limited to the area of social and educational services or social welfare. As an indication of such lack of interest, suffice to say that ID is not included in the World Bank and WHO Global Illness Burden.

There are diverse reasons for this scarce interest. First, there is no international consensus on the definition of intelligence or on how to quantify it. Second, more epidemiological studies are needed about the effect of early cognitive developmental disorders on public health in order to designate priorities and design effective interventions, especially in undeveloped countries. Third, while for distinct psychiatric disorders –from personality disorders to schizophrenia– there is an intense debate about classification criteria, in the area of ID the debate almost exclusively focuses on assigning the appropriate name to the concept and on how to evaluate skills and the kind of support needed. Fourth, there is not a sufficient amount of funds designated for ID research since it is not a key issue in national ID programs and the pharmaceutical industry is not interested in ID research. This creates a vicious circle: since there are no resources for conducting research, not enough scientific research is produced about ID for it to be incorporated into mental health policies based on the evidence, or for improving the classification and diagnosis system (for example, the International Classification of Illnesses ICD-10, Statistical Diagnostic Manual DSM-IV) or for devising good practice guidelines or other tools to guide the homogenization of socio-health care. And last, many professionals and families / service users believe that it has more to do with social or educational concepts than with a health condition.[2]

One factor that increases the difficulty in understanding the term ID is the conceptual reference framework. It is not a medical disorder, although it has an illness classification code (for example, International Classification of Illnesses, 10th version, ICD-10, 2002), and it is not a mental illness, although it is included in classifications for mental disorders (for example, the DSM-IV-TR, American Psychiatric Association, 2002). In fact, it is a type of syndrome (a metasyndrome) that is similar to the concept of dementia.[2]

ID has a prevalence of 1.5% in western countries, although this rate can increase to 4% in less developed nations[3] due to factors such as the presence of neurotoxic agents or nutritional deficiencies during pregnancy. A considerable proportion of persons with ID have plurideficiencies and medical problems. In addition, ID has consequences throughout one's lifetime and entails a significant burden for families and caregivers, demanding a high level of service provisions. ID is the principal cause of socio-health expenses, not only in the mental health sector but also in the medical field, at least in western countries.[4]

Due to its importance, it is consequently necessary to deepen the concept of ID from a comprehensive social perspective, without overlooking conceptual, nosological, medical, pharmacological and psychiatric factors.

The concept of intellectual disability

ID refers to a *particular state of intellectual and adaptive functioning*, which begins in infancy and in which limitations in intelligence coexist with attenuated cognitive, social and practical skills. The problems and deficits in the subject with ID may have a specific cause, but ID is not synonymous with an etiological factor.

The term ID includes, by definition, three essential components: a) intellectual functioning significantly below average with an intelligence quotient (IQ) less than 70 (measured using psychometric tests such as the *Wechsler Intelligence Scales for Children-Revised, Stanford-Binet, Kaufman Assessment Battery for Children*); b) a marked deficit in the ability of the individual to adapt to the daily demands of their social environment (neither of these factors –low intelligence and deficient adaptive conduct– is sufficient for establishing an ID diagnosis if they are regarded individually); and c) onset before the age of 18. Slight variations exist in the codification of the severity levels for ID, although the important division is that of mild and moderate (IQ greater than 35-40), severe (IQ 20-25 to 35-40) and profound (IQ less

than 20-25). In spite of the fact that the above divisions are generally agreed upon, the American Association on intellectual and Developmental Disabilities (AAIDD), in their latest definition (2002),[5] moves away from the importance given to date to the measurement of intelligence, which depends more on the evaluator's judgment than on intellectual tests. In addition, for the purpose of using language that is focused more on needs and less on deficits, the AAIDD proposes a new categorization for ID degrees: the need for intermittent, limited, extensive or generalized support.

It also needs to be clarified that it is necessary to view functional limitations in relation to the social and cultural context of age and cultural peers and to consider cultural and linguistic diversity, as well as differences in communication and sensorial, motor, and behavioral aspects. The fundamental objective for the evaluation and diagnosis of ID is the development of a profile of types of support necessary to enable the improved functioning of persons with ID. Finally, the subjects' abilities and skills that may contribute to such improvement should also be evaluated.[3]

Etiopathogenic and diagnostic factors

One factor in ID that contributes to conceptual problems is the heterogeneity of the etiological factors, which are summarized in table I. In addition, in 60% of persons diagnosed, the deficit or alteration that causes ID is not known. In many mild ID cases it is difficult to find a specific, underlying medical cause, although signs appear that would suggest that neurological damage or social deprivation (poverty, malnutrition, etc.) are possibilities. In this respect, Zigler[6] proposes subdividing the population of persons with ID into those who have suffered an interruption in the maturation process and those who do not reach the level expected in the population, in spite of having completely developed. The first group includes the majority of non-biological causes, especially social deprivation. The second group includes all of the causes that can be characterized as biological, since they are precisely what make average intellectual functioning impossible.

Among the diverse causes of ID, due to its importance it is worth citing genetic anomalies, that make up 30% of the cases; standing out among these, because of their high prevalence, are trisomy 21 or Down syndrome (one in 800 live births) and fragile X syndrome (five out of every 10 000 births).

Determining the causes of ID is essential for intervention since health care expenses would decrease and the response to treatment and the prevention of possible complications would improve.[7] In this respect, in recent years the term "behavioral phenotype" has been introduced, which is described by Flint and Yule as: "a characteristic pattern of motor, cognitive, linguistic, and social abnormalities that is consistently associated with a biological disorder. In some cases, the behavioral phenotype may constitute a psychiatric disorder; in others, behaviors which are not usually regarded as symptoms of psychiatric disorders may occur".[8]

Knowledge about the behavioral phenotype helps to plan and organize the care of persons with ID. Although the first behavioral phenotypes were nearly exclusively based on syndromes with genetic origins, today it is possible to talk also about behavioral phenotypes for non-genetic conditions that accompany ID –such as fetal alcohol syndrome– which are applicable to the set of ID disorders with biological origins.

It is necessary to take into account that ID can be confused with other syndromes that begin in infancy or that also involve cognitive or social functioning deficits, such as learning or communication disorders (without a connection to ID), where a developmental alteration is observed in a specific area (reading or expressive

Table I
Principal causes of syndromes that accompany intellectual disability

Cause	*Example*
Metabolic disorders:	
Lipids	Tay-Sachs Disease
Mucopolysacaridosis	Hurler Syndrome
Amino Acids	Phenylketonuria
Carbohydrates	Galactosemy
Purines	Lesch-Nyhan Syndrome
Genetic disorders:	
Neurocutaneous	Tuberous Sclerosis
Chromosomal alterations:	
Trisomy	Down Syndrome
Linked with X chromosome	Fragile X Syndrome
Microdelection	Prader-Willi Syndrome
Mutation	Smith-Lemli-Opitz Syndrome
External causes:	
Intrauterine infections	Rubella, Syphilis
Toxic substances	Fetal Alcohol Syndrome
Perinatal problems	Anoxia, Prematurity
Malnutrition, social or affective deprivation	

language, for example) but there is not a generalized affect in intellectual development and adaptive skills. In addition, it is necessary to differentiate ID from generalized development disorders that are characterized by a qualitative developmental affectation in social interaction and verbal and non-verbal social communication skills that may or may not be connected with ID.

Furthermore, ID must be distinguished from other syndromes or that are also associated with cognitive dysfunction, such as dementia or cognitive deterioration, but whose diagnosis requires that memory affectation and other cognitive deficits are significantly attenuated in comparison with prior ability levels.

Lastly, limited intellectual ability is described by an IQ interval higher than that required for ID (71-84). It is possible to diagnose ID in individuals with IQ scores between 71 and 75 if they have the characteristic deficit in adaptive behavior. In order to differentiate mild ID from limited intellectual ability, careful review of all of the available information is necessary.[9]

Health and intellectual disability

Medical advances have enabled persons with ID to live longer and have a better quality of life than in the past. Nevertheless, increased life expectancy has resulted in new medical situations (for example, a higher incidence of dementia) that, when added to the comorbility derived from the very causes of ID, require an in-depth study of medical and health factors related with ID.

This population has many difficulties in terms of access to community health services. In Europe, an appropriate response to this problem was the initiation of Project Pomona,[10] which has been carried out in European Union countries since 2002. The principal objective of this project is to identify the health indicators, based on evidence, that reflect the most important areas for improving the quality of life of and equal access to health care for persons with ID. This process in identifying factors has been conducted with the participation of subjects with ID, their families, professionals and administrators.

Project Pomona is based on the principal that health is one of the parameters for quality of life. Individuals with ID are citizens who have an inherent right to equal opportunities in terms of health care and social inclusion. Nevertheless, this is not always carried out in practice and the project, therefore, attempts to identify the factors that explain the health disparities found between persons with ID and the general population. The objective is for patients with ID to be able to make informed decisions about their own health in an autonomous manner.

Health indicators identified by Project Pomona include the following:

1. Demographic indicators: prevalence, type of housing, occupation, socio-economic status / income, life expectancy.
2. Health status indicators: epilepsy, buccal health, body mass index, mental health, auditory and mobility skills.
3. Determinants: physical activity, behavioral problems, psychopharmacological consumption.
4. Health system: hospitalization and contact with health professionals, health check-ups, health promotion, specific training of medical professionals.

Health problems for persons with ID

In recent years, it has been shown that subjects with ID not only have more health needs than general population, but also that these needs are barely covered and, when they are, the health care received is usually not adequate. Various explanations have been formulated with respect to this lack of care,[11] such as: lack of knowledge on the part of primary care doctors about common medical problems in the ID population; communication problems when interviewing a patient with ID, especially for those with severe or profound disabilities; and the existing gap in assistance between social services and health services, since nobody in particular is responsible for these individuals.

Kerr and colleagues[12] state that this population experiences the same health problems as the population without disabilities; but some are more frequent and others are more specifically related to certain syndromes that accompany ID, including:

1. Cancer: Types of cancer most often found in individuals with ID differ with respect to individuals without this disability; there is a higher incidence of gastrointestinal cancers (esophagus, stomach, gall bladder) –two times higher– in patients with ID and, to a lesser extent, malignancies of the lung, prostate, breast and cervix.[13]
2. Coronary disease: Coronary diseases are the second cause of death in persons with ID.[14] These individuals are more prone to developing hypertension and obesity and exercise is non-existent; all vulnerability factors for cardiac ischemia. Persons with Down syndrome have a greater risk of congenital cardiac disease.
3. Buccodental problems: Subjects with ID are more prone to developing cavities, tooth loss and gum disease and experience a greater number of dental

extractions. This may be due to dietary deficiency, poor dental hygiene or the inaccessibility of buccal hygiene campaigns to this population; persons with ID rarely visit the dentist. Individuals with Down syndrome possess a higher rate of buccodental problems, such as mouth deformations and gum problems.[15]

4. Diabetes: Persons with ID have a higher rate of diabetes in comparison with the general population. This may be due to the high rate of obesity, poor diets or sedentary lifestyles.[16]
5. Epilepsy: While epilepsy affects 1% of the population, it affects 33% of subjects with ID, and the percentage rises with the increased severity of ID.[17]
6. Gastrointestinal problems: Many persons with ID have high levels of *Helicobacter pylori*, especially those who have lived in institutions or shared residences.[18] Gastroesophageal Reflux Disease can affect as many as half of the subjects with ID.[19] This anomaly has been linked with fragile X syndrome and may be one of the causes for the enormous rates in cancer of the esophagus. In addition, persons with Down syndrome are more prone to colic.
7. Respiratory diseases: This is the leading cause of death in patients with ID,[20] since they are more vulnerable to respiratory tract infections due to aspiration or reflux, if they have deglutition difficulties. Persons with Down syndrome are at particular risk since they are prone to suffering pulmonary abnormalities, they have a deficient immune system and are likely to breathe through the mouth.[21] Pulmonary complications have also been reported in subjects with tuberous sclerosis.
8. Sensory problems: Auditory and visual problems are very common in these patients. It is calculated that 40% have vision problems, and the percentage is similar for auditory problems. In addition, subjects with ID are more prone to develop eye and ear infections, while they less often seek out an ophthalmologist or otorhynolaryngologist.[22]

Table II is a summary of health problems most often related with ID. Of particular interest is the one-year longitudinal study conducted by the British non-governmental organization Mencap.[23] According to this protocol, persons with ID use primary care services significantly less often than the rest of the population. Likewise, it was found that caregivers for these people expressed a great deal of frustration to medical professionals because they seldom referred patients with ID to colleagues in other specialties to meet their health care needs.

Table II
Alterations often related with intellectual disability (especially severe and profound)

System	*Disorders*
Buccopharyngeal	Dental cavities, split palate, gum disease, facial asymmetries, dislocated jaw
Sensory	Visual deficits, blindness, hypoacusis, deafness
Cardiovascular	Reduced cardiac and lung functions, especially linked to curvature of the spine; chronic respiratory infections; pneumonia
Muscular-skeletal	Curvature of the spine, for example, scoliosis, hyperlordosis, hyperkyphosis; deformities in the shoulders, elbows, hips, hands, knees and feet; hypertony and hypotony; fluctuations in muscular tone, athetosis
Dermatological	Tissue damage, especially due to pressure or incontinence
Excretory	Enuresis; encopresis; urinary tract infections; constipation; urinary retention
Central nervous system	Epilepsy

Psychiatric and behavioral disorders associated with intellectual disability

In the last two decades, the problem of mental illness in persons with ID (dual diagnosis) has received increasing attention for two fundamental reasons: a) the recognition of the rights of individuals with ID to receive appropriate medical care; in the past it was quite common that these persons, collectively, were given elevated doses of psychopharmacologic drugs –almost always antipsychotic– when their behavior became unacceptable, without taking into account the diagnosis and collateral and evolutionary effects; and b) the normalization principal is in favor of subjects with ID living in the community and utilizing its resources. In fact, treatment and care of psychiatric disorders in this population is considered to be a fundamental element of community services.

Persons with ID reflect the entire spectrum of psychiatric disorders described in the general population, but the prevalence of mental problems/disorders/illness is higher. In one-third of the cases, ID coexists with psychiatric alterations and recent studies report rates as high as 40%,[24] with 10 to 20% having behavioral problems not related to a mental illness. In 50% of the

cases, mental illness goes by undetected or is underdiagnosed, including in institutions with psychological support.[25]

If the situation of persons with ID is analyzed synoptically, the higher proclivity toward psychiatric disorders is not surprising. Publications have shown how biological alterations that often accompany ID are also vulnerability factors for mental illness. One example is the proneness to depression in persons with Down syndrome; it has been suggested that alterations in pair 21 also cause alterations in the dopaminergic system[26] and, therefore, may contribute to the higher rates seen in mood alterations. Also evident is the way in which many psychological factors in these individuals (such as low self-esteem) are vulnerability factors for mental illness. Lastly, numerous social factors, which unfortunately are very present in this population, increase the proclivity for mental illness, such as rejection, denial of opportunities, abuse, the typically frequent change in caregivers, institutionalization, etc. A more detailed analysis of the above is available in Matson and Sevin's vulnerability factors model.[27] It is important to remember that, from a biopsychosocial perspective, all of these elements likely interact with each other (table III).

Mental health care for subjects with ID is relatively new and, as a result, much is not known in this area. These theoretical gaps explain the variability that exists among data from epidemiological studies. Some prevalence studies include personality disorders, autism, attention deficit hyperactivity or dementias, but others do not identify them. The same is true with behavioral alterations, which are so frequently seen in this population. Nevertheless, there seems to be a consensus that the pathoplasty of mental illness in patients with ID is often different than that found in the non-disabled population. Depressive mood, for example, may be manifested as behavioral irregularities or irritability, the same symptoms as anxiety.[28] In these cases, the term used is "behavioral equivalents." Thus, the decision to use diagnostic criteria found in common classifications (CIE-10, DSM-IV-TR), or adapted criteria (*Diagnostic Criteria for Learning Disabilities*, DC-LD[29] or DM-ID),[30] may also result in modifying epidemiological data since many abnormalities do not satisfy sufficient criteria using standard classifications.

Likewise, Sovner[31] adds the following points as difficulties in evaluating, interpreting and diagnosing the symptoms of psychiatric disorders in persons with ID:

- The presence of *disadaptive behavior prior* to the mental illness;
- *The existence of intellectual limitations* that do not allow the patient with ID to understand the evaluator's questions or verbalize an appropriate response.
- The need to situate the symptoms within the context of the *evolutive development* of the patient. In this respect, Szymanski and King[32] state that subjects with ID have interpersonal behavior and skills patterns corresponding to earlier chronological stages (for example, infancy) and maintain these characteristics throughout their lifecycle; thus, any attempt to interpret their symptoms should be made in an evolutive context.
- The coexistence of *cognitive disorganization* in persons with ID that provokes, for example, depression to be manifested by psychotic instead of affective symptoms.

Lastly, another particularly interesting phenomenon for explaining why psychiatric problems in this population go undetected on many occasions is what Reiss calls ID's "diagnostic overshadowing."[33] This term refers to the tendency by the clinical practitioner to attribute the origin of psychiatric symptoms to ID, which results in masking mental illness; symptoms such as depressive mood and delirium are consequently attributed to ID and not to a mental illness. This impedes the implementation of corrective measures for treating the anomaly. Likewise, a distorted view is

Table III
VULNERABILITY FACTORS IN INTELLECTUAL DISABILITY (MATSON AND SEVIN, 1994)

Organic	- Physiological alterations (abnormalities in the cerebral structures or epilepsy) - Biochemical alterations (prone to the appearance of illnesses such as schizophrenia or depression) - Genetic alterations (for example, genetic relation between Down syndrome and Alzheimer-type dementia)
Behavioral	Development of behavior as a result of a complex relationship with the environment (for example, a person isolated from the rest who also presents poor adaptive skills may develop depression)
Developmental	Remaining in the maturative or cognitive development of earlier evolutive phases that may predispose the appearance of mental illness (for example, lacking the full formation of the I can predispose the appearance of schizophrenia)
Socio-cultural	Stigmatization, lack of opportunities, numerous and marked changes in caregivers, lack of economic resources, abuse, exploitation

produced in the mind of the clinician that results in the minimization of the symptoms' importance and, therefore, their diagnostic relevance. Therefore, when an adolescent with normal intelligence displays inappropriate conduct, there is a tendency to regard the subject as having a behavioral problem. If the same inappropriate conduct is displayed by an adolescent with ID, the behavior is presumed to be a result of the disability itself and is, therefore, of less concern than in the first case. Further still, the clinician must often trust reports by third persons in order to establish the diagnosis, which provokes distortions.

Another factor to be considered in ID is the presence of behavioral disorders, recognizable in 25 to 60% of adults with ID residing in the community; although this percentage decreases to 12 to 17% when involving severe behavioral irregularities.[34,35] A behavioral disorder is a set of disruptive of negative behaviors of such intensity, frequency and duration that it can put the physical security of the person or of others in danger, or that may limit or delay the delivery of ordinary community resources.[36] The principal behavioral problems associated with ID, according to the expanded inventory (Inventory for Client and Agency Planning, ICAP),[37] are the following: self-injurious behavior, aggressiveness toward or injuring others, destruction of objects, disruptive behavior, atypical and repetitive habits (stereotypical), offensive social conduct, timidity or lack of attention and cooperation. The most frequent type of behavioral problem that requires treatment, needs support and requires changes in daily life is aggressive behavior –whether against others or oneself– especially in young subjects or adolescents who are male.

The differences in prevalence data among the diverse studies are due to the various definitions of behavioral problems, the utilization of different lists for problematic behaviors, difficulty determining the group of persons who truly represent a challenge for services, and reliability problems from one observer to another because of variations in the criteria used for severity among professionals who treat the same persons.

Finally, it is important to recognize the relation between behavioral problems and mental illness. It is possible to point to the study by Rojahn and colleagues,[38] that uses the *Behavioral Problems Inventory* scales and *Diagnostic Assessment for the Severely Handicapped-II*. This protocol finds that subjects with severe or profound ID who displayed self-injurious, stereotyped or aggressive and destructive behavior generally had higher psychopathology scores; in addition, the presence of behavioral problems tripled the probability of the appearance of almost all of the psychiatric disorders.

Conclusion: What can health sciences do for persons with intellectual disability?

Medicine and health sciences in general should contribute to improving the quality of life of individuals with ID; to accomplish this, it is possible to design interventions that are closely related with the diagnosis.[39] All available information about possible etiological factors must be taken into account (for example, precipitating episodes, family disposition, specific biological deficits, personality problems and specific developmental difficulties). Factors such as the severity of the ID, related disorders, the effects of prior treatments and the social environment should also be considered. Due to the complexity of ailments in persons with ID, their treatment must be planned from diverse perspectives (pharmacology, psychotherapy, behavioral intervention, etc.). In this regard, Ferrell and colleagues[40] propose a combined therapeutic model based on community support, along with neuropsychiatric measures, as a type of effective intervention for psychiatric and behavioral problems in persons with ID.

Nevertheless, for a long time the only medical response to the problems experienced by subjects with ID has been the unrestricted provision of antipsychotics for the control of behavioral problems, as well as institutionalization of this individuals in psychiatric institutions; this has generated rejection of and generally discredited psychopharmacology in this field. Currently, there are consensual guidelines and recommendations for the psychopharmacological treatment of this population.[39,41] Contributions by the Royal College of Psychiatrists, Birmingham University and the Mencap Association should be noted,[42] who have developed a set of indications for psychopharmacological treatment and reviewed the scientific evidence.

Prescribing doses and guidelines are the same as those that apply to the general adult population, though increases in and the suspension of medications should occur over a longer period of time. In the case of psychotic and severe behavioral disorders in which an environmental, organic or affective cause has been ruled out, the atypical antipsychotics that have been studied the most in this population are risperidone, followed by olanzapine[28] (a second choice is haloperidol and, third, clozapine, while taking into account leukogram values). Table IV lists some general indications.

The principal problem faced by a medical professional when considering the psychopharmacological treatment of mental disorders in the ID population is the variability of syndromes. This situation, in turn, provokes different medical, psychiatric and behavioral symptoms as compared to the general population, which

entails enormous difficulties in establishing a psychiatric diagnosis, determining a prognosis for standard treatments, and detecting possible undesirable effects and adverse reactions to medication. Added to this is the scarcity of specific studies about the effectiveness and safety of using psychopharmacological medications in patients with ID. Nearly all are single-case studies, case series, retrospective reviews and open trials.

Furthermore, the results of controlled studies with heterogeneous samples of persons with ID are suspect, since the biological differences between a person with Down syndrome and another with Angelman syndrome, for example, are much greater than those observed between adults in the general population. In fact, controlled trials should be conducted in subjects with the same or similar etiological diagnosis. Another factor that should not be overlooked is the enormous individual variability in the response to and appearance of secondary effects in these patients and the lack of acute and subacute facilities for individuals in crisis, in such a way as to be able to control therapeutic guidelines.

It is reasonable to act with extreme caution, make an appropriate diagnosis, implement individualized therapeutic changes (without modifying several medication regimens at one time) and instruct the patient's family in accordance with national guidelines. In this respect, it is also worth remembering the old four rules for medical treatment by Cecil Loeb: a) if the prescribed treatment works, don't change it; b) if the prescribed treatment does not work, suspend it; c) if you do not know what to do, do not do anything; d) whatever you do, do not let your patient wind up in the hands of the surgeon!

In response to the high degree of unsatisfied health needs in the ID population, the following action steps have been suggested:[43]

1. Preparation: familiarization and knowledge of places (hospital, medical office), procedures and medical techniques.
2. Longer consultation time: with the goal of enabling persons with ID to discuss their health problems.
3. Informal and non-threatening environment: modifying the environment in order to attain a non-threatening space that helps to reduce the stress and anxiety felt by these patients in a situation such as a doctor's visit.

The U.S. Public Health Service published a report in 2002[44] that highlighted general lines of action in the field of ID for health services:

1. Integrate the promotion of health for persons with ID into community health care environments.
2. Increase knowledge about health factors related to ID and put into practice this knowledge.
3. Improve the quality of health care for patients with ID.
4. Institute training programs for professionals who provide health care to subjects with ID.
5. Guarantee that the health system produces good health indicators and results for persons with ID.
6. Increase the accessibility of health services to individuals with ID.

In Europe, similar recommendations have been developed.[45] This all leads to laying the groundwork so that in the near future the health sciences will give ID the consideration needed by this group.

Table IV
PSYCHOPHARMACOLOGICAL RECOMMENDATIONS FOR INTELLECTUAL DISABILITY

Medication	*Symptoms*	*Observations*
Antipsychotics	Psychotic symptoms Self-injurious behavior Behavioral problems	Atypical antipsychotics are preferable (risperidone) Depot antipsychotics if there is no treatment observation
Mood stabilizers	Bipolar disorder Mania episode Aggressive behavior Agitation Psychiatric or behavioral problems in patients with epilepsy	Valproic acid or lithium for bipolar disorder; in agitation cases also use SSRI* antidepressants or atypical antipsychotics
Antidepressants	Depression Suicidal ideation/behavior Self-injurious behavior Aggressive behavior Agitation, anxiety	Use of SSRI preferred; evaluate use of delayed action in case of anxiety Also use benzodiacepines; in case of suicidal ideation/behavior, also administer mood stabilizers

* SSRI: Selective Serotonin Reuptake Inhibitors

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2. La salud mental en la discapacidad intelectual.

En las últimas dos décadas, la salud mental en personas con DI (o diagnóstico dual) ha recibido una atención creciente por dos razones fundamentales: el reconocimiento del derecho de las personas con DI a recibir los cuidados médicos apropiados y el principio de inclusión, que apoya el que las personas con DI vivan en la comunidad y utilicen sus recursos.

Como apuntábamos en el primer artículo presentado en esta tesis: *Intellectual Disability, an approach from the health sciences perspective*, las personas con DI exhiben todo el rango de trastornos psiquiátricos descritos en población general, sin embargo la prevalencia de éstos es más elevada (Campbell & Malone, 1991; Menolascino & Fleisher, 1991; Borthwick-Duffy, 1994; Whitaker & Read, 2006; Cooper et al. 2007). En una tercera parte de los casos, la DI co-existe con trastornos psiquiátricos, señalando estudios recientes tasas de hasta un 40% de problemas de salud mental (Cooper, 2007, ver tabla 1).

TABLA 1. Prevalencia de enfermedades mentales (Cooper et al. 2007)

Categoría diagnóstica	Dgtico clínico (n=1023) %	Dgtico DC-LD (n=1023) %	Dgtico CIE-10 (n=1023) %	Dgtico DSM-IV-TR (n=1023) %
Trastornos psicóticos 1	4.4	3.8	2.6	3.4
Trastornos afectivos	6.6	5.7	4.8	3.6
Trastornos de ansiedad 2	3.8	3.1	2.8	2.4
TOC	0.7	0.5	0.2	0.2
Trastornos orgánicos	2.2	2.1	1.9	1.7
Abuso de sustancias	1.0	0.8	0.8	0.8
Pica	2.0	2.0	0	0.9
Trastornos del sueño	0.6	0.4	0.2	0.2
TDAH	1.5	1.2	0.5	0.4
Trastornos del espectro autista	7.5	4.4	12.2	2.0
Problemas de conducta	22.5	18.7	0.1	0.1
Trastornos de personalidad	1.0	0.8	0.7	0.7
Otros trastornos mentales	1.4	0.8	0.7	0.4
Enfermedades mentales, excluyendo problemas de conducta y TEA	22.4	19.1	14.5	13.9
Enfermedades mentales, excluyendo TEA	37.0	32.8	14.6	14.0
Enfermedades mentales, excluyendo problemas de conducta	28.3	22.4	16.5	15.6
TOTAL PROBLEMAS DE SALUD MENTAL	40.9	35.2	16.6	15.7

1 Incluye trastornos esquizoafectivos
2 Excluye fobias específicas

La atención a la salud mental de las personas con DI es relativamente reciente, de ahí que todavía queden muchas lagunas en este ámbito. Estos vacíos teóricos dan cuenta de la variabilidad encontrada entre los datos de estudios epidemiológicos. Algunos estudios de prevalencia incluyen trastornos de personalidad, autismo, déficit de atención por hiperactividad, demencias, mientras que otros no. Lo mismo sucede con las alteraciones de conducta, tan frecuentes en esta población. Sin embargo, sí parece haber un consenso acerca de que la patoplastia de la enfermedad mental en las personas con DI es en muchas ocasiones diferente a la encontrada en la población sin discapacidad. El humor depresivo, por ejemplo, puede manifestarse en forma de alteraciones conductuales o irritabilidad, lo mismo que los síntomas de ansiedad. En estos casos se habla de "equivalentes conductuales" (Hemmings et al, 2006), conductualizándose los síntomas cognitivos. Es por ello que la decisión acerca de utilizar los criterios diagnósticos de las clasificaciones habituales (CIE-10, DSM-IV-TR) o criterios adaptados (Diagnostic Criteria for Learning Disabilities; DC-LD (Royal College of Psychiatrists, 2001), o el DM-ID (NADD, 2007; Down España, 2011) puede igualmente hacer variar los datos epidemiológicos, pues si empleamos las clasificaciones estándar muchas de las patologías no cumplirán los criterios suficientes.

Como desarrollaremos a lo largo de este trabajo, si nos detenemos brevemente a analizar la situación de las personas con DI, no resulta extraño este dato que pone de manifiesto su mayor vulnerabilidad a padecer un trastorno psiquiátrico.

Se ha señalado en la literatura cómo las alteraciones biológicas que generan una DI son a la vez factores de vulnerabilidad para la enfermedad mental, recibiendo este fenómeno el nombre de fenotipos conductuales (introducido por Nyhan en 1972). Se define el fenotipo conductual como la conducta en sentido amplio (aspectos cognitivos e interacción social) asociada a un síndrome específico con etiología genética, en el cual no existe duda de que el fenotipo es resultado de la lesión subyacente (Flint & Yule, 1994; Artigas, 2002). Un concepto mucho más amplio es el de Harris, 1987, quien propone considerar fenotipo conductual todo trastorno de conducta que no sea aprendido. Aunque las primeras aproximaciones a los fenotipos conductuales se hicieron de forma exclusiva a partir de síndromes con origen genético, actualmente se puede hablar también de fenotipo conductual en condiciones no genéticas que cursan con DI, como por ejemplo el síndrome alcohólico fetal, haciéndolo extensivo a los trastornos de origen biológico.
Otro ejemplo sería la vulnerabilidad a la depresión de las personas con Síndrome de Down, donde se ha postulado que las alteraciones del par 21 también causan alteraciones en el sistema dopaminérgico (Collacott et al 1992), y que por tanto podrían dar cuenta de esas mayores tasas

de alteraciones del estado de ánimo.

También resulta claro cómo muchos de los factores psicológicos (p.ej., la baja autoestima o un apego inseguro) de estas personas son factores de vulnerabilidad para la enfermedad mental. Por último, numerosos factores sociales como el rechazo, la negación de oportunidades, los abusos, los marcados cambios de cuidadores, las institucionalizaciones, etc., desgraciadamente muy presente en esta población, resultan obvios factores de incremento de la vulnerabilidad a padecer una enfermedad mental.

Sin embargo, pese a esta elevada y comprensible prevalencia, la población con discapacidad intelectual rara vez recibe un diagnóstico psiquiátrico, pese a padecerlo (Reiss et al., 1982; Reiss et al., 1983; Alford & Locke, 1984; Garner et al., 1994; Spengler y Strohmer, 1994; Spengler et al., 1990; White et al., 1995; Salvador et al, 2000; Jopp & Keys, 2001), recibiendo este fenómeno el nombre de “efecto eclipsador” de la discapacidad intelectual (diagnostic overshadowing). Este término se refiere a la tendencia del clínico a atribuir como causa de los síntomas psiquiátricos la propia discapacidad intelectual, eclipsando ésta la presencia de la enfermedad mental. Así, los síntomas, como por ejemplo humor depresivo o delirios, se achacarían al hecho de presentar DI en vez de a la presencia de una enfermedad mental, y por tanto no se podrían en marcha las actuaciones correctas para atajar la problemática de estas personas. De igual modo, se produce una distorsión en la mente del clínico, minimizando la importancia de los síntomas y, por tanto, su significación diagnóstica. Con esto, cuando un adolescente con inteligencia normal presenta de modo manifiesto una conducta inapropiada, se considera que el chico tiene un problema conductual. Cuando la misma conducta inadecuada la presenta un adolescente con DI, se tiende a presuponer que tal conducta resulta de su propia discapacidad, y que además no es tan preocupante como en el primer caso. Además, con frecuencia el clínico debe confiar en los informes de terceras personas para realizar su diagnóstico, lo que puede provocar distorsiones.

Otro de los factores a tener en cuenta en la DI es la presencia de trastornos de conducta, presentes en alrededor del 25-60% de los adultos con DI residentes en la comunidad, aunque estas cifras bajan a un 12-17% si nos referimos a alteraciones graves de conducta (Emerson, 1995, 2002). Cuando hablamos de problema o trastorno de conducta, nos referimos a una conducta de tal intensidad, frecuencia o duración que provoca que la seguridad física de la persona o de los demás se encuentre probablemente en serio peligro, o la conducta que probablemente limite o retrase seriamente el acceso y el uso de los recursos comunitarios ordinarios (Emerson, 1987). Los principales tipos de problemas de conducta en la DI, según el inventario más extendido (Inventory for Client and Agency Planning, ICAP) son: comporta-

mientos autolesivos o daño a sí mismo, heteroagresividad o daño a otros, destrucción de objetos, conducta disruptiva, hábitos atípicos y repetitivos (como estereotipias), conducta social ofensiva, retraimiento o falta de atención y conductas no colaboradoras. Los tipos de problemas conductuales que determinan una demanda de atención, necesidad de apoyo y alteración de la vida diaria más frecuente son las conductas hetero y auto-agresivas, sobre todo en usuarios jóvenes o adolescentes de sexo masculino.

Las diferencias en los datos de prevalencia entre diferentes estudios se deben a las diferentes definiciones de problemas de conducta, la utilización de diferentes listas de conductas problemáticas, las dificultades para decidir el grupo de personas que realmente representan un reto para los servicios y a problemas de fiabilidad entre distintos observadores, ya que el criterio de gravedad cambia entre los distintos profesionales que atienden a una misma persona.

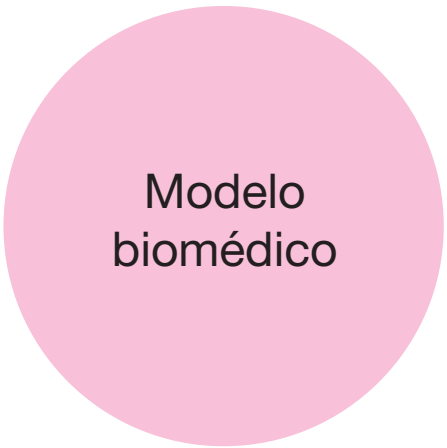
3. Nuestro marco para entender la salud mental en las personas con discapacidad intelectual. Los modelos bio-psico-social y de diátesis-estrés.

El objetivo de este proyecto de tesis es el de desengranar parte del entramado de porqué la discapacidad intelectual constituye en sí misma un factor de vulnerabilidad a las enfermedades mentales. Como hemos visto, la discapacidad intelectual es un concepto escurridizo, y con génesis e implicaciones biopsicosociales, al igual que lo es el fenómeno de la enfermedad mental. De ahí que se nos despliegue un mapa con multitud de variables que interactúan entre ellas si queremos entender el porqué de la discapacidad intelectual como factor de vulnerabilidad en la aparición de enfermedades mentales.

Para entender la génesis de las enfermedades mentales, tomamos dos modelos, que además de ser los mayormente aceptados por la comunidad científica, encierran el enfoque holístico con el que nos propusimos abordar la problemática, a saber: el modelo biopsicosocial –ampliado posteriormente por la OMS en su Clasificación Internacional del Funcionamiento- y el de diátesis-estrés.

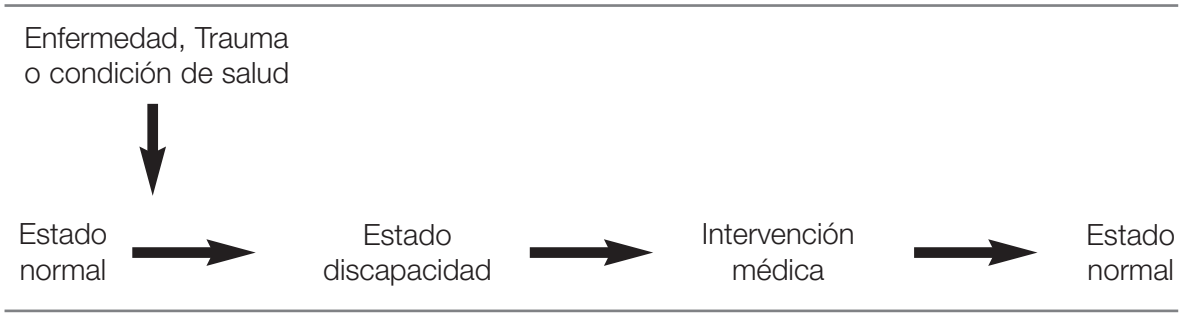
Para llegar a ellos, deberemos hacer previamente un breve recorrido por los modelos de enfermedad/discapacidad.

El modelo biomédico



Históricamente la discapacidad ha sido considerada como el resultado de una enfermedad, trauma u otra condicón de salud. De ahí que las personsas con discapacidad eran considerados como seres “anormales”, desviados de la norma, de lo “sano”. Por ello eran comúnmente identificados por su condición patológica (un “cojo” un “subnormal”, un “loco”), haciendo hincapié en que era el individuo el que llevaba consigo su discapacidad.

3. Nuestro marco para entender la salud mental en las personas con discapacidad intelectual. Los modelos bio-psico-social y de diátesis-estrés.



El Figura 2. Modelo lineal y unidireccional

Ésta es la perspectiva que subyace al modelo biomédico, que describe la salud como la mera ausencia de enfermedad. Bajo este modelo, los tratamientos y las intervenciones son medios para cambiar el estado de enfermedad al estado de salud, siendo por tanto un modelo que conlleva una práctica unidireccional (Figura 2).

> Nuestro sistema actual de Servicios Sociales, pese a incluir el término minusvalía (recientemente intercambiado por el de discapacidad) basa sus sistemas clasificatorios en el grado de retraso mental, consistente con el modelo biomédico, si bien la nueva clasificación de la Ley de Dependencia y Autonomía Personal, es más coherente con modelos que veremos más adelante.

Pese a que el modelo biomédico es en la actualidad el más dominante entre los modelos de salud, modelos más holísticos y bidireccionales como el biopsicosocial y sus extensiones, están instaurándose con fuerza, dadas las limitaciones del modelo biomédico al no tener en cuenta ni al individuo ni a la sociedad al describir el concepto de discapacidad.
Estas limitaciones se hacen especialmente relevantes a la hora de proponer medidas de resultados de las intervenciones, así cómo a la hora de diseñar las mismas. Medir el síntoma en lugar de, por ejemplo, la calidad de vida, o en discapacidad intelectual, tomar como medida de mejora de la intervención el CI en lugar de la capacidad de, por ejemplo, usar el transporte público. En cuanto al tipo de intervenciones, emplear programas de mejora cognitiva o facilitar el uso de una calculadora para mejorar el manejo del euro.

El modelo social

Las limitaciones anteriormente mencionadas del modelo biomédico, ya apuntadas por Parson en 1958 con su *conducta de enfermedad*; o en 1963 por Goffman al hablar de *estigmatización, marginación y desviación*, llevaron al pendulazo de la aparición del modelo social.

Modelo social

Como se establece en los postulados de Hahn al hablar de discapacidad, *el problema radica en el fracaso de la sociedad y del entorno creados por el ser humano para ajustarse a las necesidades y aspiraciones de las personas con discapacidad y no en la incapacidad de dichas personas para adaptarse a las demandas de la sociedad.*

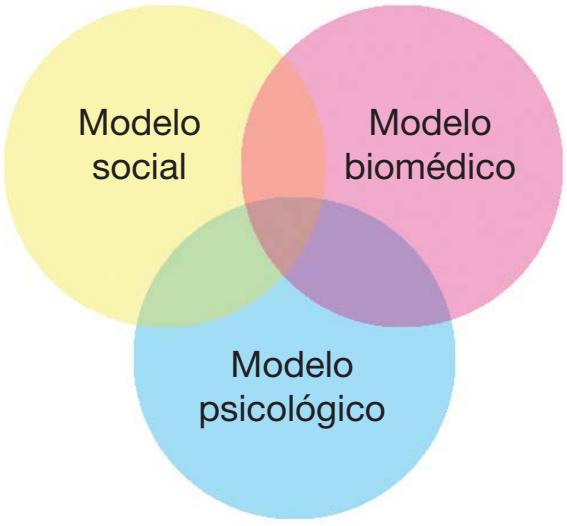
En contraste con el modelo biomédico, el modelo social postula que la discapacidad reside en la inadecuación de la sociedad para adaptarse al individuo, y no en el individuo.

Esto lleva a afrontar los problemas derivados de la discapacidad de una manera radicalmente opuesta. Desde esta perspectiva no abordamos el síntoma de aumentar el CI para que una persona con discapacidad intelectual se desenvuelva en el medio, sino que se abren un sinfín de nuevas intervenciones: desde cambiar la imagen que la sociedad tiene de las personas con discapacidad intelectual, o utilizar las nuevas tecnologías para la orientación en el transporte, o trasladarnos la pregunta de: ¿dónde reside la discapacidad de una persona que utiliza silla de ruedas, en su lesión medular en que hemos creado un mundo con escaleras en lugar de rampas?

El modelo psicológico

El modelo psicológico no suele describirse de manera separada, quedando normalmente integrado en las descripciones de bien el modelo biomédico o del modelo social. Sin embargo haremos aquí un breve apunte, pues el modelo psicológico, a caballo entre ambos, describe la discapacidad como algo más inherente al individuo, si bien contempla las influencias del entorno en la formación de esta visión psicológica. Más en línea con el modelo social, el modelo psicológico eleva el papel de la percepción de la condición de uno mismo a la descripción de la discapacidad, abriendo de nuevos caminos para la intervención. La baja autoestima de las personas con discapacidad intelectual ante una sociedad que los percibe como inferiores, o el apego inseguro por la mayor dificultad de una madre de establecer un vínculo y transmitir incondicionalidad ante un hijo que no cumple los estándares sociales, son claros ejemplos de la interacción de discapacidad intelectual y vulnerabilidad a la enfermedad mental.

El modelo biopsicosocial

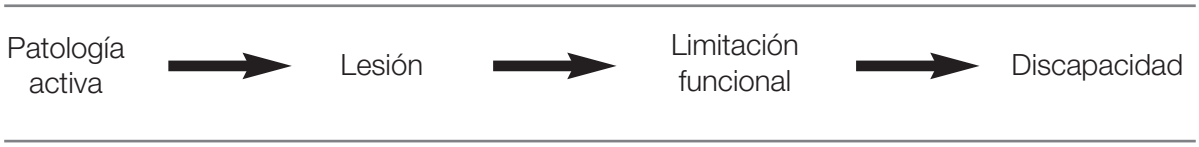


El modelo biopsicosocial, definido por G. Engel, en 1977 en la revista *Science*, hace converger los modelos biomédicos, sociales y psicológicos.
Engel propuso este marco como una alternativa a la predominancia del modelo biomédico, y no sólo en la comprensión de la enfermedad, sino en la práctica clínica. Es un modelo holístico, interpretando la salud como la interacción de las tres perspectivas (biomédica, social y psicológica), que aunque estén interrelacionadas, también pueden actuar de manera independiente. Si bien con él se alcanza la glo-

balidad de la descripción de la salud y la discapacidad, se le ha echado en cara el no recoger factores específicos que contribuyan a su desarrollo. De ahí que haya derivado en dos visiones complementarias, el modelo de discapacidad de Nagi y el modelo de la OMS, bajo el desarrollo de la CIF.

El modelo de discapacidad de Nagi.

Desarrollado a principios de los 60 por el sociólogo Saad Nagi como parte de su trabajo para entender la discapacidad en la Administración de la Seguridad Social de los Estados Unidos (SSA), este modelo describe cuatro fenómenos básicos que Nagi consideraba fundamentales para el tratamiento: patología activa –active pathology-, lesión –impairment-, limitación funcional –functional limitation- y discapacidad –disability- (Figura 3).



El Figura 3. El modelo de discapacidad de Nagi.

• Patología activa describe la interrupción de los procesos habituales que derivan en una desviación del estado normal. Por ejemplo: infección, trauma, enfermedades, o condiciones degenerativas.

• Lesión es la pérdida completa o daño en las estructuras o sistemas corporales normales. El modelo introduce como la patología active suele derivar en deficiencias, mientras que no siempre sucede a la inversa. Por ejemplo, una deficiencia como el síndrome de X frágil, no deriva de patología activa, mientras que una discapacidad intelectual por síndrome alcohólico fetal sí.

• Limitación funcional son las restricciones en la ejecución que encuentra el individuo. Por ejemplo, el daño cerebral puede entorpecer el razonamiento abstracto.

• Discapacidad la expresa limitación física, intelectual o sensorial en un determinado contexto social.

Al igual que el modelo biopsicosocial, el modelo de Nagi contempla la discapacidad como una interacción entre el individuo y la sociedad. Asimismo, sugiere que las acciones sociales encaminadas a acomodarse a la patología reducirán la discapacidad del individuo.
A mediados de los 90, varias revisiones fueron sugeridas para el modelo de Nagi. En 1994, Vergbrugge & Jette expandieron el modelo añadiendo:

- Factores socioculturales: aquellos que pertenecen al entorno físico y social.

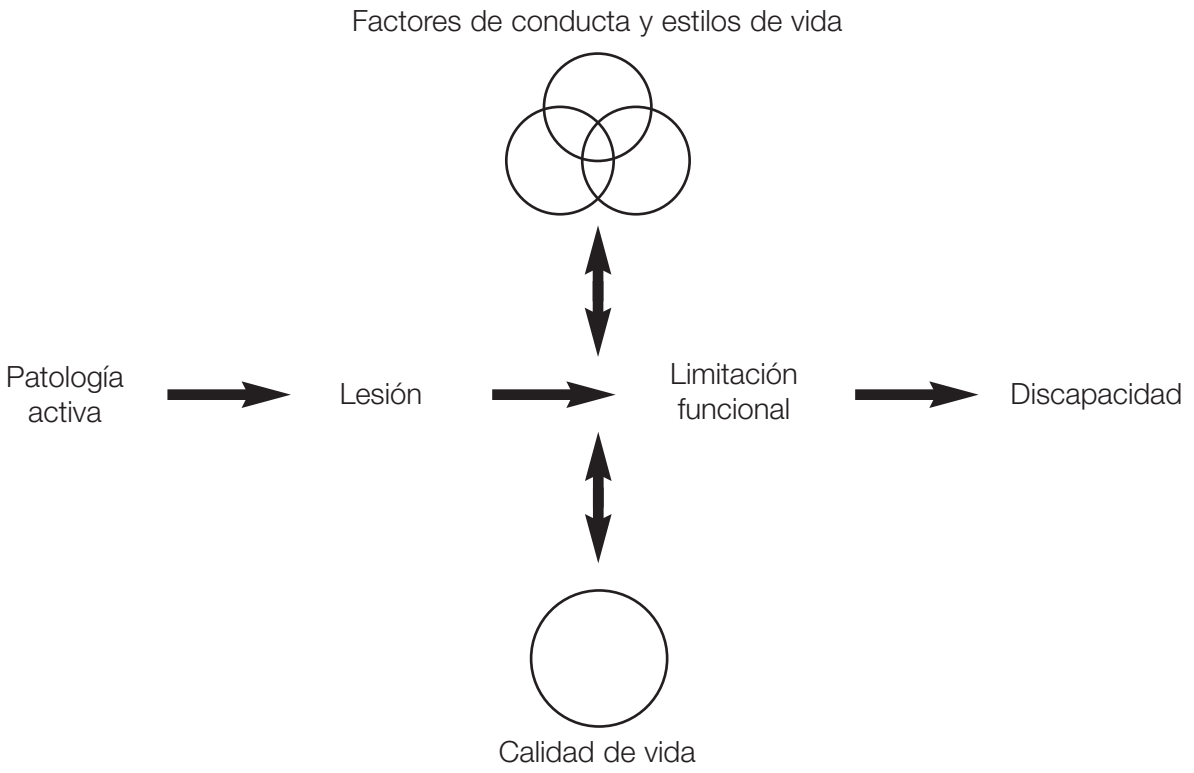
- Factores personales: aquellos que pertenecen al individuo (conductas, estilos de vida..)

Estas adhesiones al modelo fueron un intento de desarrollar una definición completa del fenómeno bio-psico-social, definiendo la discapacidad como "el impacto que condiciones crónicas o agudas tiene en el funcionamiento de los sistemas corporales específicos y en la habilidad de los individuos para actuar de la manera necesaria, usual, esperada y personalmente deseada por la sociedad." Proponiendo también que la discapacidad es fluida, y es capaz de mudar en tipo, severidad y consecuencias.

Otra expansión paralela del modelo fue la del informe Disability in America del Institute of Medicine (IOM). En dicho informe, Pope & Tarlov expandieron el modelo original de Nagi añadiendo dos nuevos e importantes conceptos: factores de riesgo y calidad de vida. Los factores de riesgo incluyen factores biológicos, ambientales (físicos y sociales), y de conducta/estilos de vida capaces de interactuar con el proceso discapacitante. De igual modo, la calidad de vida podía afectar y verse afectada en cada estadio del proceso de discapacidad.

En 1997, un segundo informe de la IOM, *Enabling America* volvió a expandir el modelo. En primer lugar, eliminaron el concepto de discapacidad, posicionándolo como resultado de la interacción del individuo y su ambiente. En segundo lugar, definieron el concepto de discapacidad a través de un proceso de "capacitar-discapacitar", identificando la discapacidad como cambiante y reversible, y por lo tanto definida como bidireccional (Figura 4).

3. Nuestro marco para entender la salud mental en las personas con discapacidad intelectual. Los modelos bio-psico-social y de diátesis-estrés.



El Figura 4. Modelo del IOM (1991)

Por último, los factores de riesgo fueron renombrados como factores transicionales, por considerarlos responsables de las transiciones entre las categorías responsables del proceso de "capacitar-discapacitar".

El modelo IOM modificado también enfatiza la importancia de la interacción del individuo con el ambiente, añadiendo también los factores psicológicos además de los ya contemplados físicos y sociales.

El modelo de la Organización Mundial de la Salud (OMS)

El segundo marco actual que expande el modelo bio-psico-social comenzó su andadura en los años 70 de manos de la OMS. Pese a desarrollarse de manera independiente al modelo de Nagi, aborda casi los mismos conceptos que éste último. El primer modelo de discapacidad de la OMS, la Clasificación Internacional de Deficiencias, Discapacidades y Minusvalías (CIDDM) –WHO, 1980; OMS, 1983- forma

parte de la familia de clasificaciones de la CIE-10. LA CIDDM identifica tres conceptos fundamentales: deficiencias, discapacidades y minusvalías. Este modelo, al igual que el original de Nagi, es un modelo lineal, en el que el proceso tiene su origen en la deficiencia. (Figura 5).

El Figura 5. Modelo de la CIDDM, 1980.

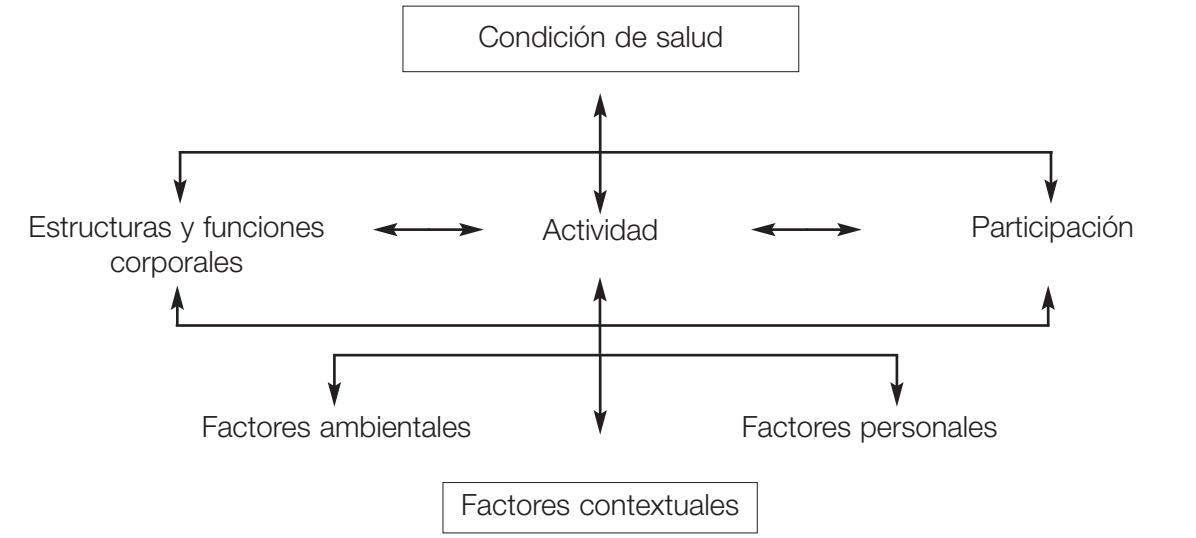
- **Deficiencia**, definida como pérdida o anormalidad de una estructura o función psicológica, fisiológica o anatómica del individuo (nivel órgano).

- **Discapacidad**, como restricción o ausencia debida a la deficiencia de la capacidad de realizar una actividad dentro del margen que se considera normal (nivel individuo).

- **Minusvalía**, entendida como la situación de desventaja que surge en un individuo como consecuencia de una deficiencia o discapacidad que limita o impide el desempeño de un rol que es normal en su caso (nivel social).

Además de la linealidad, que incidía en el origen de la discapacidad situada dentro del individuo, la CIDDM, al igual que le modelo biomédico, centraba su taxonomía en los aspectos negativos.
Por ello, en 2001, la OMS publicó una nueva versión bajo la que entender la discapacidad: La Clasificación Internacional del Funcionamiento y la Discapacidad (CIF). El marco de la CIF describe los cambios en la salud como la interacción dinámica entre la condición de salud y los factores del contexto (Figura 6).

3. Nuestro marco para entender la salud mental en las personas con discapacidad intelectual. Los modelos bio-psico-social y de diátesis-estrés.



El Figura 6. El Modelo CIF (2001)

Como en le modelo bio-psico-social en el que hunde sus raíces, el modelo de la CIF describe la salud atendiendo a tres niveles que incluyen el cuerpo, el individuo y la sociedad. En cada nivel, la CIF identifica tres dominios de funcionamiento (p.e. estructuras corporales y funciones) así como niveles de discapacidad asociados (p.e. deficiencias, limitaciones y restricciones).

Al igual que el modelo biopsicosocial original y el modelo de Nagi, el modelo de la CIF también reconoce los componentes individuales y sociales como intervinientes en el concepto de salud. Contempla dos categorías de factores contextuales: factores ambientales y factores personales. Los factores ambientales incluyen elementos tales como las actitudes sociales, las características físicas o arquitectónicas, el sistema legal, el clima… Los factores personales incluyen elementos como la edad, el género, clase socioeconómica, estrategias de afrontamiento, educación, personalidad…

Por último, el modelo de la CIF también incluye las premisas del Modelo Universal de Zola, 1989, que rechaza una sociedad dividida entre aquellos que tienen discapacidad y aquellos que no, entendiendo que la discapacidad no es sintomática sino una rasgo presente en todos, y que por lo tanto debe ser entendida como un continuo. Curiosamente, además de en el planteamiento de continuidad del concepto, se pretendió recoger este modelo en el nombre, hablando de Funcionamiento y no de Discapacidad.

Conclusiones

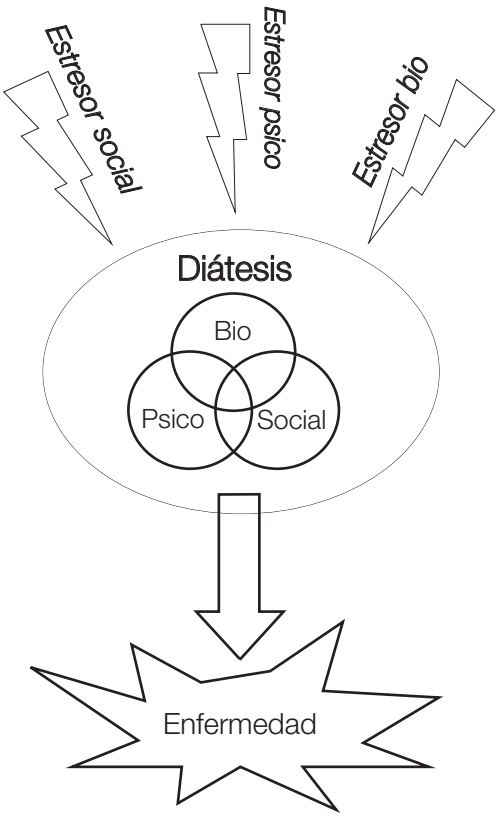
Como puede verse, el marco para entender el desarrollo de una enfermedad mental, o de la discapacidad intelectual en la que se asienta, ha ido aumentando de complejidad con el tiempo. Sin embargo, sí parece claro que si queremos obtener una visión global del fenómeno no podemos desatender estos modelos que nos indican la interacción de muy diversos factores.

El modelo de diátesis-estrés

En paralelo al modelo al biopsicosocial, el modelo de diátesis-estrés establece un paradigma más causal que también puede arrojar luz al tema que nos ocupa. Dicho modelo examina la relación entre la diátesis y un estresor y cómo los efectos de esta dinámica influyen sobre el individuo y sobre la génesis de la enfermedad.

La diátesis es la predisposición a padecer una enfermedad, predisposición que puede encontrar su origen en (o en la combinación de) factores biológicos, psicológicos o sociales. El estrés es la respuesta que un individuo experimenta ante eventos vitales, que de nuevo pueden tener un origen biológico, psicológico o social. Cuando estos eventos vitales superan las capacidades de afrontamiento del individuo y éste presenta ya una predisposición diatética, es cuando puede surgir la enfermedad. Sin embargo, las dos condiciones son necesarias, pero no suficientes, este caso explicado por los factores protectores (Carson et al, 2002; Zubin & Spring, 1977).

Engranando con los planteamientos actuales de la psicología positiva y de las teorías de resiliencia, los factores protectores son todas aquellas características intrínsecas o extrínsecas que rodean al individuo y que le guían hacia la salud. Este reconocimiento de que hay factores moduladores que previenen el determinismo del modelo de diátesis-estrés, no sólo abren el modelo a nuevos planteamientos de prevención sino que, al igual que el modelo social, amplían el abanico de intervenciones, en este caso a través del desarrollo y fortalecimiento de los factores de protección (Giménez et al; 2010; Vázquez et al., 2009).



Modelo propuesto para la comprensión del origen de los problemas de salud mental en las personas con discapacidad intelectual.

Como hemos apuntado en el capítulo 2, las personas con discapacidad intelectual presentan una mayor vulnerabilidad a la aparición de problemas de salud mental, en este caso enfermedades mentales y alteraciones de conducta.

Planteamos, acorde con los planteamientos de Holland (Holland, 1999) un modelo híbrido entre el modelo biopsicosocial y el de diátesis estrés como marco para entender esta mayor vulnerabilidad (tabla 2).

Tabla 2. Sistemas de Intervención Global. La perspectiva biopsicosocial y diátesis-estrés

	Diátesis	Estrés	Protectores
Biológicos	- Fenotipos conductales	- Menstruacción - baja estimulación (liberación de endorfinas)	- Estimulación (Snoezlen)
Psicológicos	- Baja autoestima - Apego inseguro - Menores habilidades de comprensión	- Frustración	- Habilidades sociales
Sociales	- Abuso y maltrato - Alienación social - Institucionalización	- Eventos vitales	- Fortalecimiento familiar - Empleo

El modelo que proponemos y que guiará los análisis que desarrollamos posteriormente, presenta muchos beneficios a la hora de entender qué factores intrínsecos a la discapacidad intelectual dan cuenta de la mayor vulnerabilidad a padecer enfermedades mentales, entendiendo cuáles de ellos tienen un origen diatético, formando parte del individuo, y cuáles un papel estresor, extrínseco a él.

4. Objetivos.

4.1. Justificación del estudio.

Cómo se ha expuesto en los capítulos anteriores, dada la complejidad para entender el concepto de discapacidad intelectual, enfrentarse al porqué de la mayor vulnerabilidad a los problemas de salud mental debe abordarse desde una perspectiva holística. Proponemos el modelo híbrido de diátesis-estrés y biopiscosocial para afrontar el planteamiento, intentando con ello reflejar la pluralidad de interrelaciones que intervienen en la aparición y retroalimentación de una enfermedad mental en una persona con discapacidad intelectual.

4.2. Objetivo principal.

Nuestro objetivo es por tanto analizar diferentes aspectos intervinientes en las enfermedades mentales de las personas con discapacidad intelectual desde diferentes posiciones del modelo híbrido de diátesis-estrés y biopiscosocial.

4.2.1. Objetivo específico 1: diátesis-estrés.

Exponer, utilizando las variables de eventos vitales y eventos traumáticos, la diferencia en la génesis de la enfermedad mental en personas con discapacidad intelectual de un factor diatético y un factor desencadenante.

4.2.2. Objetivo específico 2: interrelación con el sistema familiar.

Entender cómo la aparición de una enfermedad mental afecta al sistema familiar, y cómo éste también influye en la génesis, mantenimiento y forma de la enfermedad mental.

4.2.3. Objetivo específico 3: interrelación con una variable macro social; el acceso al empleo.

Demostrar las implicaciones de la mayor vulnerabilidad a la enfermedad mental en variables macro sociales como el acceso al empleo, incidiendo por tanto en la necesidad de un marco de comprensión del fenómeno de la enfermedad mental en las personas con discapacidad intelectual macrosistémico.

5. Material and methods.

5.1. Participants.

All both clients and their key informants of the Carmen Pardo-Valcarce Foundations' sheltered workshops in Madrid were interviewed for the present study. During the time of the study, 180 adults with intellectual disabilities were working at the Foundation's sheltered workshops, all of which were asked to participate along with their main carers. Only one client and two key informants did not give their consent for the interview, being the final sample with complete data of 177. Regarding clients, participants were 62 females (35%) and 115 males (65%), with a mean age at the time of the study of 29.6 years (SD = 6.6).

Degree of disability according to ICD-10 (WHO, 1994) and based on the initial assessments (WAIS-III, Weschler, 2001 and adaptative skills WHO-DAS II) accounted for 127 clients with mild intellectual disabilities (72%) and 50 with moderate intellectual disability (28%). Regarding key informants, 159 (95%) were the parents of the client with whom the client was still living (139 (83%) mothers; 20 (12%) fathers), and for the 10 clients living in residential settings, first degree relatives with whom the client had a close relationship were interviewed (6 sisters and 4 mothers).

Table 1.

	Clients	
Gender	61 female 116 male	(34.5%) (65.5%)
Age	X = 29.62 SD = 6.616	
ID*1	127 mild 50 moderate	(72%) (28%)

	Key informants	
Gender	157 female 20 male	(89%) (11%)
Age	X = 58 SD = 8,9	
Socio cultural status *2	88 Less than 7 years 47 Basic 30 Undergraduate 12 University	(50%) (27%) (16%) (7%)
Relation to client	147 mother 20 father 10 others	(83%) (12%) (5%)

*1 Assessed through WAIS-III and WHO-DAS II
*2 According to number of years of education

5.2. Instruments.

Data were gathered administering a battery of different tests to both users/workers and carers. Three psychologists with wide experience in intellectual disability were addressed to assess the participants. The assessed variables and the instruments used for the evaluation are listed below:

5.2.1. Degree of ID.

Intellectual evaluation was carried out using the Spanish version of the *Wechsler Adult Intelligence Scale – Third Edition* (WAIS-III) (Wechsler 2001) that includes the traditional 11 tests from the previous version plus three new tests: *matrices, symbol search and letter-number series.*

Functioning. The *World Health Organization Disability Assessment Schedule – Second Version* (WHO-DAS II) was originally published in 1988 by the World Health Organization (WHO) in order to provide a simple tool for evaluating disturbances in social adjustment and behaviour in people with mental disorders (World Health Organization 2000). The second version of the WHO-DAS scale considers the impact of any disorder on everyday functioning and is conceptually compatible with the WHO's *new International Classification of Functioning, Disability and Health* (ICF) (World Health Organization 2001). Domains assessed by the WHO-DAS II include *understanding and communicating, getting around, self care, getting along with others, household and work activities, and participation in society*. The direct score used ranges from 36 to 180.

5.2.2. Mental Health problems.

The presence of psychiatric symptoms was assessed via the Spanish version of the *Psychiatric Assessment Schedule for Adults with Developmental Disability* (PAS-ADD 10) (Gonzalez-Gordon et al. 2002b) in order to evaluate the potential presence of psychiatric disorders (Moss et al. 1993;Moss et al. 1997;Moss et al. 1995). The PAS-ADD is a semi-structured interview for use with respondents who have intellectual disability and for key informants. Based on items drawn from the SCAN *(Schedules for Clinical Assessment in Neuropsychiatry)*, it includes features such as parallel interviewing of patient and informant, a three-tier structure to provide a flexible interview

appropriate to the patient's intellectual level and simplified wording. However, in our study the CATEGO 5 algorithms were not used because they have shown lack of validity for the Spanish version (Gonzalez-Gordon et al. 2002a). Therefore, after the interview, psychiatric diagnoses were made by an expert group designated for the study (composed of one expert psychiatrist and two expert psychologists).
Post-traumatic stress syndrome and obsessive compulsive disorder are not explored in the PAS-ADD interview, so a separate short interview elaborated for the study and also based on the SCAN was used. Simple phobias were not evaluated for the present study. Personality disorders were not either because they are not included in the PAS-ADD interview.

The PAS-ADD interview includes a checklist of life-events experienced over the previous 12 months (see table 1) which was assessed through key informants. It is not clearly stated how this checklist was built, but contents are similar to other life events lists (Hastings et al., 2004). The sum of all the life events experienced over the previous 12 months was the variable used.

Behavioural problems. The *Inventory for Client and Agency Planning* (ICAP) (Bruininks et al. 1986;Montero 1996) is a tool designed for the assessment of adaptative and maladaptative behaviour and gathers additional information to determine the type and amount of social assistance that people with disability may need In our study, the ICAP was used only with the purpose of evaluating behavioural problems, since functioning was already assessed by means of the WHO-DAS II. The general maladaptative index ranges from +5 to -70. High negative scores indicate severe behavioural problems.

5.2.3. Self-determination.

Elaborated by Michael Wehmeyer and published in 1995, the *Arc's Self-Determination Scale* (ARC'S) is a self-report scale that provides a measure of the construct 'self-determination' (Wehmeyer 1995). It has been designed for people with disability (particularly, intellectual and learning disabilities) and consists of 72 items grouped in four sections. Partial scores in each section evaluate the following features associated to the concept of self-determination: *autonomy, self-regulation, empowerment and self-realisation*. Altogether, these measures result in a global score of self-determination. A higher score implies a higher level of self-determination. Maximum score is 148 points.

5.2.4. Traumatic events.

Allen's Trauma History Screen (Allen et al. 1999) was also administered to key informants. The Trauma History Screen was initially developed to screen for potentially traumatic events in women admitted for specialized treatment of trauma-related disorders, though has afterwards been used in multiple settings (Gibbs & Rude, 2004) and has also been validated into Spanish with acceptable data regarding reliability and validity (Landeta & Calvete, 2002). The questionnaire contains 14 items (see table 2 for more details) assessing possible occurring traumas, and respondents indicate the frequency with which they have experienced the traumas as well as the age at which the trauma occurred. In the present study and in order to match with the life events checklist, the sum of the traumatic events was the variable used.

5.2.5. Family Burden.

See articles 7.1. Validación en población española de la entrevista de carga familiar objetiva y subjetiva (ECFOS-II) en familiares de pacientes con esquizofrenia and 7.2. Validation of the Subjective and Objective Family Burden Interview (SOFBI/ECFOS) in primary caregivers to adults with intellectual disabilities living in the community.

6. La delgada línea roja entre diátesis y estrés. Los eventos vitales y los eventos traumáticos.

6. La delgada línea roja entre diátesis y estrés. Los eventos vitales y los eventos traumáticos.

Para esta diferenciación entre eventos estresores y factores diatéticos, seleccionamos dos variables sociales: los eventos vitales y los eventos traumáticos. Tras una revisión del estado de la cuestión de ambos factores (Martorell & Tsakanikos, 2008), llevamos a cabo un estudio de regresión para determinar la relación entre ambos y exponer la importancia de diferenciar un factor de vulnerabilidad de un factor de estrés o desencadenante (Martorell et al 2009).

Se han realizado muy pocos estudios al respecto hasta la fecha, si bien es un tema de grandes implicaciones en la comprensión de la salud mental de las personas con discapacidad intelectual. Los eventos traumáticos constituirían una diátesis para las enfermedades mentales, mientras que los eventos vitales representarían un ejemplo de factor estresor. Ambos tipos de eventos están significativamente más presentes en las vidas de las personas con discapacidad intelectual, pero diferenciarlos es de gran importancia para la comprensión y para el diseño de intervenciones. La literatura de la salud mental de las personas con discapacidad intelectual suele tratarlos indistintamente, con graves consecuencias. Estudios del rigor como el de Cooper et al 2007, incluyen bajo el mismo paraguas eventos vitales y eventos traumáticos, entendiéndolos como factores de vulnerabilidad. Lo mismo sucede con el uso del PAS-ADD, que acompaña un checklist de eventos vitales y que puede llevar a la confusión de que los mismos que enumera dicho checklist son factores de vulnerabilidad (aún más, dicho checklist ni siquiera cuenta una validación estadística ni bibliográfica pese a su extendido uso). Como se desarrolla en la publicación, son muchos los estudios que equiparan ambos aspectos, igualando diátesis a estrés. Sin embargo, entender los eventos estresores como factores de vulnerabilidad puede llevar a prácticas iatrogénicas, en las que se restrinjan las actividades vitales de las personas con discapacidad intelectual, por intentar no exponerlas a factores de vulnerabilidad, cuando no son tales (no salir de casa por si le atracan, no tener apenas actividades por los estresores de cambios de actividad, etc).

Esta diferenciación queda reflejada en nuestro estudio, no sólo conceptualmente, sino metodológicamente. Tanto los eventos vitales como los traumáticos son significativos para el modelo cuando tenidos en cuenta por separado. Esta significación estadística es esperable, pues como hemos ilustrado en el modelo de diátesis-estrés, tanto los factores de vulnerabilidad como los desencadenantes son condiciones necesarias para que se instaure la enfermedad. Sin embargo, de no existir una predisposición de vulnerabilidad, los eventos vitales en sí mismos no son consustanciales a la enfermedad, es más, son consustanciales a la vida de cualquier ser humano, de ahí la importancia de no tratarlos indistintamente: un atraco, el fallecimiento de un ser querido, una pérdida de ingresos… forman parte de nuestras vidas. Y pese a ser vividos de forma desagradable, enriquecen nuestras vidas y nos hacen crecer. Son los factores de vulnerabilidad los que nos hacen frágiles, los factores tanto biológicos, como psicológicos, como sociales que se fraguan con nosotros al

construirnos como seres humanos y que dejan grietas en nuestra estructura por las que se resquebraja el ser ante un golpe vital. Este argumento casi existencial, se refleja burdamente en el análisis de regresión de nuestro estudio, pues al ser introducidos conjuntamente en el modelo, los eventos vitales pierden su significación, pues son los factores de vulnerabilidad los que dan cuenta de la enfermedad mental.

6.1. Traumatic experiences and life events in people with intellectual disability.

Traumatic experiences and life events in people with intellectual disability

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Purpose of review

The aim of this article is to present and critically evaluate recent research on life events and traumatic experiences as predictors of psychopathology in people with intellectual disability.

Recent findings

The area has not developed significantly in the last years. Although life events have been associated with a range of mental health problems, only few studies have tried to clarify their role in psychopathology. It is often the case that differences between life events and traumatic experiences have been overlooked, mainly because establishing a clear cut-off point between the two types of events is not always possible. In addition, traumatic experiences *per se*, and as potential predictors of psychopathology, have been scarcely investigated in people with intellectual disability.

Summary

The role of recent life events and traumatic experiences across the life-span of people with intellectual disability deserves more research. An outstanding question is whether these events are risk factors or triggering factors, as well as how to differentiate between traumatic and life events. Identifying possible protective factors for mental health seems to be a very promising line for future research with important clinical implications.

Keywords

intellectual disability, life events, mental health, psychopathology, traumatic experiences, vulnerability models

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Introduction

The recent literature has often supported that people with intellectual disabilities (PWID) tend to present higher rates of mental health disorders than those without intellectual disabilities (i.e. Cooper *et al.* [1•] and Smiley *et al.* [2•], but see also Whitaker and Read [3]), suggesting an increased bio-psycho-social vulnerability to psychopathology. Biological factors, such as behavioural phenotypes, psychological factors, such as low self-esteem and insecure attachments, and social–external factors, such as life events, are often salient in PWID. It is therefore possible that the interaction of these factors may account for the high rates of mental health problems in PWID. In this context, understanding the role of life events and traumatic experiences becomes particularly important.

Past research of life events and traumatic experiences

The impact of recent life events has been extensively studied in PWID [4–12] and frequently has been taken into account in vulnerability models [13,14]. Very little research, however, has been conducted on traumatic experiences across the life span, except for isolated experiences, such as sexual abuse [15–18] and understanding posttraumatic stress disorder (PTSD) in PWID [19,20].

The thin red line between life events and traumatic experiences

According to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM)-IV diagnostic criteria a traumatic event is defined as involving actual or threatened death or serious injury of self or others causing immediate intense fear, helplessness or horror. In contrast, a life event is an experience with a determinable origin and limited duration, which can influence someone's psychological status and can markedly change the social or physical environment [5], for example moving house or residence. An obvious question is whether life events and traumatic experiences are different concepts or part of a continuum [21]. Establishing a clear separation line is a difficult task as 'nontraumatic' life events may become 'traumatic' in PWID due to difficulties in understanding and analysing situations (e.g. getting lost in a subway station). Lower

levels of intellectual functioning have been associated with higher rates of PTSD [22], suggesting that the range of potentially traumatic experiences is greater in PWID.

In this sense, the developmental perspective [23] may perhaps shed more light on the cut-off point between traumatic experiences and life events when such experiences trespass the frontier of 'beareable' to 'unbearable'. The developmental level at which trauma occurs has a major impact on the capacity of the victim to adapt [24]. For example, the level of self-perception of coping skills or self-regulation can determine the processing of an event, so that the same event may be experienced either as nontraumatic (at a higher developmental level) or as traumatic (at a lower developmental level).

Life events

In the period of this review, Tsakanikos *et al.* [25••] examined the impact of multiple life events on mental health in adults with intellectual disabilities in a cross-sectional study design. Data revealed that single exposure to life events was significantly associated with female sex, schizophrenia, personality disorders and depression. Multiple exposure to life events, however, was associated with personality disorder, depression and adjustment reaction. Investigating multiple exposure (cumulative impact of life events) as a stressor can be especially informative, as it can potentially demonstrate a cut-off point for the number and severity of life events that could trigger mental health problems.

In this same period, a longitudinal study (2-year follow-up) with adolescents was published by Gunther *et al.* [26••] that examined the contribution of exposure to bullying and adverse life events (family-related or school-related) in the development of psychopathology, along with the potential moderating effects of neighbourhood social capital. Both variables were found to predict an increase in psychopathology. Exposure to bullying was associated with the development of hyperactivity and emotional problems, while the experience of adverse life events (especially family-related) predicted the development of behavioural problems. Neighbourhood social capital did not seem to moderate the effects. The inclusion of potential moderating variables opens future research lines, mainly on protective factors, with obvious implications for clinical practice.

A number of risk factor studies have also looked at life events *inter alia*, given that such events are often followed by presentation of both mental health disorders and behavioural problems [27]. Cooper *et al.* [1•] in a population-based study ($n = 1023$) investigated a large number of factors independently associated with mental ill health, including number of life events, which turned out to be significant. While trying to establish incidence rates, Smiley *et al.* [2•] carried out a prospective cohort study to identify predictors of mental ill health. In this study, it was shown that preceding life events predicted incident ill health (it should be noted that under the term 'life events' traumatic experiences were also included). Furthermore, Cooper *et al.* [28] tried to establish the prevalence, incidence and predictive factors of mental ill health but this time in a population-based prospective cohort study of 184 adults with profound intellectual disabilities. Life events in the previous 12 months were again significant predictors of mental ill health. It should be noted that this study examined exclusively recent life events (not including long-term traumatic experiences), suggesting that the effect seemed greater than for Smiley *et al.* [2•], signalling a greater impact when the degree of disability is higher, perhaps because people with profound intellectual disabilities are likely to experience greater difficulty in understanding changes and relationships between events.

In a prevalence study of psychiatric disorders in children, Emerson and Hatton [29] also looked at a large number of possible risk factors among children with and without intellectual disabilities, finding that exposure to two or more negative life events significantly increased the odds of psychiatric disorders, especially emotional disorders and conduct disorder. Investigating the presentation and risk factors for depression in adults with intellectual disabilities, McGillivray and McCabe [30] found that, along with automatic negative thoughts, social support, self-esteem, and life events that occurred over a 6-month period were significant predictors of clinical depression. Finally, Soni *et al.* [31] investigated the course and outcome of psychiatric illness in adults with Prader–Willi syndrome in a follow-up study. Recent life events were more likely to be experienced in the follow-up period by those participants with recurrent episodes of psychiatric disorders, suggesting that life events could play the role of precipitating factors when vulnerability factors such as the behavioural phenotype of Prader–Willi syndrome are present.

Traumatic experiences

Research activity in this area has mainly focused on the types and effects of traumatic experiences, although the role of these experiences as a risk factor in vulnerability models has been overlooked. Abuse is the more frequently studied type of trauma. Reiter *et al.* [32••] found that students with intellectual disabilities were abused (physical, sexual and emotional) more frequently than their peers. Moreover, it was shown that not only is there a higher incidence of victimization of PWID, but the abuse often goes unreported; or, when reported, it tends to be disregarded. In line with previous research, Reiter

et al. [32••] also found a higher probability of repeated victimization, proposing that the high incidence of abuse of PWID calls for action.

Murphy *et al.* [33••] have employed retrospective interviewing assessing skills and behavioural problems 3 months prior to the abuse (*Time 1*), immediately after the abuse (*Time 2*) and 3 months after the abuse (*Time 3*). This study revealed a consistent pattern of impact in adults with severe intellectual disabilities: fewer problems or difficulties at *Time 1*, major difficulties at *Time 2* and some recovery by *Time 3*. Employing observable measures can be very helpful for identifying possible abuse in people with severe intellectual disabilities as they are less able to report them. Despite the study limitations due to the small number of participants, data also suggested that few cases reached criminal court, it was common to move the victim's placement following abuse and therapeutic services were scarcely offered to victims.

In a broader sample, including participants with intellectual disabilities, Brownlie *et al.* [34] found that participants (especially girls and women) with language impairments were more likely than those with unimpaired language to report sexual abuse, after controlling for differences in socioeconomic status. A study of life histories [35] suggested that the development of a self-injury/self-harm conundrum in individuals with severe intellectual disabilities might be a response to traumatic life experiences. In this same line, and also through case studies, Taggart *et al.* [36] found that the less frequent phenomenon of misuse of alcohol and drugs in PWID may also be a consequence of 'psychological trauma' and 'distance from the community'. Multiple deaths of close family members, death of partners, long-term physical, emotional and financial abuse, sexual abuse or rape were also identified in the case studies.

Finally, Peckham [37•] has published three papers related to sexual abuse. The first paper was a review of sexual abuse in PWID, highlighting consequences such as PTSD, low self-esteem, anger, depression, guilt, relationship problems and behavioural problems such as self-harm, stereotypical behaviour and sexualized behaviour. The second paper described a survivors group for women with intellectual disabilities [38•], and the last one evaluated the therapeutic group effectiveness using a repeated measure design [39•]. The survivors group pilot for women improved sexual knowledge, trauma and depression but neither self-esteem nor anger, and behavioural problems worsened before improving. In terms of interventions, Focht-New *et al.* [40] offer strategies and guidance for assessment for PWID exposed to interpersonal violence and crime, based on the authors' clinical experience and on previous evidence-based knowledge.

Conclusion

Understanding the role of recent life events and traumatic experiences as predictors of psychopathology in PWID is particularly important. Identification of risk factors can shed light on aetiological processes, identify sub-groups that should be targeted for prevention and suggest how interventions and services should be implemented [14]. Importantly, investigation of possible protective factors when risk factors are present has been overlooked, so there is scope for further research in this area, which can inform both clinical theory and practice.

Regarding future research, longitudinal studies are needed to establish the role of life events, and traumatic experiences in particular, in the development of psychopathology. The majority of the recently published papers regarding traumatic experiences are case studies and literature reviews, so there is scope for empirical research on the role of traumatic experiences in the development of psychopathology. Furthermore, no sufficient evidence is available to establish clear-cut distinctions between negative life events and traumatic experiences.

Finally, there is a need to establish the role of life events and traumatic experiences in a diathesis model. As stated by Soni *et al.* [31], life events are triggers (also highlighted by the fact that they are usually measured during the previous 12 months), and they should be studied in their interaction with possible vulnerability factors such as traumatic experiences across the life span.

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References and recommended reading

Papers of particular interest, published within the annual period of review, have been highlighted as:

- • of special interest
- •• of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (pp. 518–519).

1 • Cooper SA, Smiley E, Morrison J, *et al.* Mental ill-health in adults with intellectual disabilities: Prevalence and associated factors. Br J Psychiatry 2007; 190:27–35.

This is the most recent and largest population-based study clarifying prevalence rates of mental-ill health in adults with intellectual disabilities. Although not central to the aims of the study, the number of life events was found to be significantly associated with mental ill-health.

2 • Smiley E, Cooper SA, Finlayson J, *et al.* Incidence and predictors of mental ill-health in adults with intellectual disabilities. Br J Psychiatry 2007; 191:313–319.

The authors tried to establish incidence rates and to identify predictors of mental ill-health in a prospective cohort study. Preceding life events were shown to be significant predictors for mental health problems. Further analysis of these variables, however, demonstrated that both traumatic experiences and life events were considered together under the term 'past experiences', and include parental death, parental divorce, compulsory removal from family home, known abuse, neglect or exploitation, financial poverty, other traumatic experiences and long-stay hospital residence.

3 Whitaker S, Read S. The prevalence of psychiatric disorders among people with intellectual disabilities: An analysis of the literature. J Appl Res Intell Disabil 2006; 19:330–345.

4 Ghaziuddin M, Alessi N, Greden JF. Life events and depression in children with pervasive developmental disorders. J Autism Dev Disord 1995; 25:495–502.

5 Coe DA, Matson JL, Russell DW, *et al.* Behavior problems of children with Down Syndrome and life events. J Autism Dev Disord 1999; 29:49–156.

6 Hastings RP, Hatton C, Taylor JL, Maddison C. Life events and psychiatric symptoms in adults with intellectual disabilities. J Intell Disabil Res 2004; 48:42–46.

7 Hatton C, Emerson E. The relationship between life events and psychopathology amongst children with intellectual disabilities. J Appl Res Intell Disabil 2004; 17:109–117.

8 Owen DM, Hastings RP, Noone SJ, *et al.* Life events as correlates of problem behavior and mental health in a residential population of adults with developmental disabilities. Res Dev Disabil 2004; 25:309–320.

9 Hamilton D, Sutherland G, Iacono T. Further examination of relationships between life events and psychiatric symptoms in adults with intellectual disability. J Intell Disabil Res 2005; 49:839–844.

10 Patti PJ, Amble KB, Flory MJ. Life events in older adults with intellectual disabilities: Differences between adults with and without Down Syndrome. J Policy Pract Intell Disabil 2005; 2:149–155.

11 Esbensen AJ, Benson BA. A prospective analysis of life events, problem behaviours and depression in adults with intellectual disability. J Intell Disabil Res 2006; 50:248–258.

12 Esbensen AJ, Benson BA. Diathesis-stress and depressed mood among adults with mental retardation. Am J Ment Retard 2006; 111:100–112.

13 Dekker MC, Koot HM. DSM-IV disorders in children with borderline to moderate intellectual disability. 1: Prevalence and impact. J Am Acad Child Adolesc Psychiatry 2003; 42:915–922.

14 Wallander JL, Dekker MC, Koot HM. Risk factors for psychopathology in children with intellectual disability: A prospective longitudinal population-based study. Intell Disabil Res 2006; 50:259–268.

15 Turk V, Brown H. The sexual abuse of adults with learning disabilities: Results of a two year incidence survey. Ment Handicap Res 1993; 6:193–216.

16 Westcott HL, Jones DPH. The abuse of disabled children. J Child Psychol Psychiatry 1999; 40:497–506.

17 Firth H, Balogh R, Berney T, *et al.* Psychopathology of sexual abuse in young people with intellectual disability. J Intell Disabil Res 2001; 45:244–252.

18 Sequeira H, Hollins S. Clinical effects of sexual abuse on people with learning disability: Critical literature review. Br J Psychiatry 2003; 182:13–19.

19 Mitchell A, Clegg J. Is posttraumatic stress disorder a helpful concept for adults with intellectual disability? J Intell Disabil Res 2005; 49:552–559.

20 Turk J, Robbins I, Woodhead M. Posttraumatic stress disorder in young people with intellectual disability. J Intell Disabil Res 2005; 49:872–875.

21 Ben-Ezra M, Aluf D. Traumatic events *v.* life events: Does it really matter? Br J Psychiatry 2006; 188:83–84.

22 Macklin ML, Metzger LJ, Litz BT, *et al.* Lower precombat intelligence is a risk factor for posttraumatic stress disorder. J Consult Clin Psychol 1998; 66:323–326.

23 Dosen A. Integrative treatment in persons with intellectual disability and mental health problems. J Intellect Disabil Res 2007; 51:66–74.

24 Tomasulo DJ, Razza NJ. Posttraumatic stress disorder. In: Fletcher R, Loschen E, Stavrakaki C, First M, editors. Diagnostic manual: intellectual disability (DM-ID). A textbook of diagnosis of mental disorders in persons with intellectual disability. Kingston: NADD Press; 2007. pp. 365–378.

25 •• Tsakanikos E, Costello H, Holt G, Bouras N. Multiple exposure to life events and psychiatric symptoms in people with intellectual disability. Soc Psychiatry Psychiatr Epidemiol 2007; 42:24–28.

The study introduced an analysis of multiple exposure to life events in vulnerability models of mental ill health.

26 •• Gunther N, Drukker M, Feron F, Van Os J. No ecological effect modification of the association between negative life experiences and later psychopathology in adolescence: A longitudinal community study in adolescents. Eur Psychiatry 2007; 22:296–304.

This is the only longitudinal study (2-year follow-up) in the review period, stating that life events predict psychopathology and behavioural problems. The possible effects of the moderating variable 'neighbourhood social capital' was also examined, although it did not seem to be significant.

27 Allen D, Davies D. Challenging behaviour and psychiatric disorder in intellectual disability. Curr Opin Psychiatry 2007; 20:450–455.

28 Cooper SA, Smiley E, Finlayson J, *et al.* The prevalence, incidence, and factors predictive of mental ill-health in adults with profound intellectual disabilities. J Appl Res Intell Disabil 2007; 20:493–501.

29 Emerson E, Hatton C. Mental health of children and adolescents with intellectual disabilities in Britain. Br J Psychiatry 2007; 191:493–499.

30 McGillivray JA, McCabe MP. Early detection of depression and associated risk factors in adults with mild/moderate intellectual disability. Res Dev Disabil 2007; 28:59–70.

31 Soni S, Whittington J, Holland AJ, *et al.* The course and outcome of psychiatric illness in people with Prader-Willi syndrome: Implications for management and treatment. J Intellect Disabil Res 2007; 51:32–42.

32 •• Reiter S, Bryen DN, Shachar I. Adolescents with intellectual disabilities as victims of abuse. J Intellect Disabil 2007; 11:371–387.

In an exploratory investigation, the authors employed a relatively high number of participants ($n = 100$) and a control group with no intellectual disability to explore abuse in PWID. Abuse was found to be a more frequent traumatic event among students with intellectual disability.

33 •• Murphy GH, O'Callaghan AC, Clare ICH. The impact of alleged abuse on behaviour in adults with severe intellectual disabilities. J Intellect Disabil Res 2007; 51:741–749.

A retrospective interviewing study (mainly descriptive due to the small number of participants) assessed skills and behavioural problems related to abuse. The authors found a consistent pattern of impact in adults with severe intellectual disability. Research on typical patterns of observable measures may be very helpful for identifying possible abuses in people with severe intellectual disability.

34 Brownlie EB, Jabbar A, Beitchman J, *et al.* Language impairment and sexual assault of girls and women: findings from a community sample. J Abnorm Child Psychol 2007; 35:618–626.

35 Lovell A. Learning disability against itself: the self-injury/self-harm conundrum. Br J Learning Disab 2007; 17 Oct [Epub ahead of print].

36 Taggart L, McLaughlin D, Quinn B, McFarlane C. Listening to people with intellectual disabilities who misuse alcohol and drugs. Health Soc Care Community 2007; 15:360–368.

37 • Peckham NG. The vulnerability and sexual abuse of people with learning disabilities. Br J Learning Disab 2007; 35:131–137.

This is a review of sexual abuse in PWID, highlighting consequences such as PTSD, low self-esteem, anger, depression, guilt, relationship problems and behavioural problems such as self-harm, stereotypical behaviour and sexual behaviour.

38 • Peckham NG. The delivery of a survivors' group for learning disabled women with significant learning disabilities who have been sexually abused. Br J Learning Disab 2007; 35:236–244.

This presents an interesting description of how to prepare and develop a survivor's therapeutic group for women with intellectual disability who have been sexually abused.

39 • Peckham NG. Evaluating a survivors group pilot for women with significant intellectual disabilities who have been sexually abused. J Appl Res Intell Disabil 2007; 20:308–322.

Using a repeated measure design, the authors evaluated the effectiveness of the above mentioned survivor's group, which turned out to improve their sexual knowledge, trauma and depression but neither self-esteem nor anger. They also found that the behavioural problems within the therapeutic group worsened before improving.

40 Focht-New G, Clements PT, Barol B, *et al.* Persons with developmental disabilities exposed to interpersonal violence and crime: strategies and guidance for assessment. Perspect Psychiat Care 2008; 44:3–13.

6.2. The role of recent life events and traumatic experiences across the life span.

Mental Health in Adults With Mild and Moderate Intellectual Disabilities

The Role of Recent Life Events and Traumatic Experiences Across the Life Span

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Abstract: The aim of the present study is to investigate the association between recent life events and traumatic experiences across the life span and psychiatric disorders in people with ID.

One hundred seventy-seven individuals with mild and moderate intellectual disability and their principal carers were assessed. Psychiatric disorders were evaluated with a semistructured psychiatric interview, the Psychiatric Assessment for Adults with Developmental Disabilities. This interview also includes a checklist of life events experienced over the previous 12 months, which was assessed through key informants. Presence of traumas was assessed through Allen's trauma history screen, also administered to key informants. After a descriptive analysis, binary logistic regression was used to see whether traumatic events and life events predicted the presence of ICD-10 disorders.

A 75% of the participants had experienced at least 1 traumatic event during their life span, and 50% of the participants had experienced at least 1 life event in the 12 months previous to the study. Binary logistic regression showed that exposure to 1 or more traumatic experiences significantly increased the odds of a mental disorder (OR = 1.8), as did exposure to life events (OR = 1.4). However, when both life events and traumatic experiences were entered together in the model, calculation of odds ratios revealed that traumatic experiences significantly increased the odds of ICD-10 disorders (OR = 1.7) although life events were no longer significant.

Though they have been less studied by the literature regarding predictors of mental illness in people with intellectual disability, traumatic experiences seem to play a more important role in psychopathology than life events.

Key Words: Life events, trauma, intellectual disability, psychiatric disorders.

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A number of studies have shown higher rates of mental health disorders in people with intellectual disability (ID), compared with those without ID (Campbell and Malone, 1991; Menolascino and Fleisher, 1991; Borthwick-Duffy, 1994; Cooper et al., 2007; but also see Whitaker and Read, 2006), suggesting an increased biopsychosocial vulnerability (ICF, WHO, 2001; Matson and Sevin, 1994). Greater vulnerability in people with ID is probably the result of both external and internal factors including increased dependency on others and reduced cognitive mechanisms to cope with stressful events. Life events such as bereavement, loss of a job, or serious financial problems are stressful experiences that require substantial adjustment efforts, and can trigger psychopathological manifestations in vulnerable individuals (Brown and Harris, 1989; Paykel, 2001; Tiet et al., 2001a; Goodyer, 1993). It is, therefore, not surprising that the impact of recent life events has been relatively studied in people with ID (Coe et al., 1999; Dekker and Koot, 2003; Hastings et al., 2004; Hatton and Emerson, 2004; Owen et al., 2004; Hamilton et al., 2005; Esbensen and Benson, 2006; Tsakanikos et al., 2007). However, very little research has been conducted on traumatic experiences across the life span, except for isolated experiences, such as sexual abuse (Turk and Brown, 1993; Westcott and Jones, 1999; Firth et al., 2001; Sequeira and Hollins, 2003).

It has often been claimed that the presence of ID increases the number, severity, and impact of a wide range of recent life events (Bramston et al., 1999; Tiet et al., 2001b; Hatton and Emerson, 2004). Although the impact of a wider range of traumatic experiences has been overlooked, probably because of some overlap between the 2 classes of events (given in Ben-Ezra and Aluf, 2006), it is conceivable that the presence of ID may also increase the number, severity, and impact of traumatic experiences across life span.

Consequently, the purposes of the present study were to: (*a*) re-examine the documented relationship between recent life events and ICD-10 disorders; (*b*) examine the relationship between ICD-10 disorders and traumatic experiences across the life span; (*c*) look into the outcomes of a model where both traumatic and life events were introduced together, to throw some light on the impact of these negative experiences.

METHOD

Participants

All clients, and their key informants, of the Carmen Pardo-Valcarce Foundation's sheltered workshops in Madrid were interviewed for the present study. These sheltered workshops belong to the ID network of the Madrid Regional Administration's Department of Social Services, which is the main network for people with ID in this city. During the time of the study, 180 adults with intellectual disabilities were working at the Foundation's sheltered workshops, all of whom were asked to participate, along with their main carers. Only 1 client and 2 key informants did not give their consent for the interview, resulting in a final sample of 177. Regarding clients, participants were 62 women (35%) and 115 men (65%), with a mean age at the time of the study of 29.6 years (*SD* = 6.6). Degree of disability based on ICD-10 criteria (WHO, 1994) was obtained through the Foundations' initial assessments including Wechsler Adult Intelligence Scale-III (WAIS-III) (Weschler, 2001). There were 127 clients with mild ID (72%) and 50 with moderate ID (28%). Regarding key informants, there were 159 (95%) parents (139 or 83% mothers; 20 or 12% fathers), and 10 first-degree relatives.

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Assessments

Data on psychiatric symptoms and recent life events were gathered using the Psychiatric Assessment for Adults with Developmental Disabilities (PAS-ADD) (Moss et al., 1993; 1997). The PAS-ADD is a semi-structured interview for use with respondents who have ID and for key informants. PAS-ADD is based on items drawn from the Schedules for Clinical Assessment in Neuropsychiatry (WHO, 1994b; Vázquez-Barquero, 1994), and it includes such features as: parallel interviewing of patient and informant; a 3-tier structure to provide a flexible interview appropriate to the patient's intellectual level; use of a memorable "anchor event" in the patient's life to improve time focus; and simplified wording, improved organization and layout. The overall interview is completed in approximately 1 hour. After the interview, ICD-10 (WHO, 1994a) diagnoses were made by an expert group designated for the study (1 specialist psychiatrist and 2 specialist psychologists). Posttraumatic stress syndrome and obsessive-compulsive disorder are not explored in the PAS-ADD interview, so a separate short interview elaborated for the study, also based on the Schedules for Clinical Assessment in Neuropsychiatry, was employed. It must also be noted that though problem behaviors are also categorized in the ICD-10, the PAS-ADD does not analyze them and were therefore not included in the present study. The same must be said about personality disorders.

The PAS-ADD interview also includes a checklist of life events experienced over the previous 12 months (as given in Table 1), which was assessed through key informants. The sum of all the life events experienced over the previous 12 months was the variable used.

Finally, Allen's trauma history screen (Allen et al., 1999) was also administered to key informants. The Trauma History Screen was initially developed to screen for potentially traumatic events in women admitted for specialized treatment of trauma-related disorders, though has been used in multiple settings (Gibbs and Rude, 2004) and has been translated into Spanish with acceptable data regarding reliability and validity (Landeta and Calvete, 2002). The questionnaire contains 14 items (Table 2), assessing possible traumas, and respondents indicate the frequency with which they have experienced these traumas, as well as the age at which the trauma occurred. In the present study, the sum of the traumatic events was employed as an independent measure.

TABLE 1. Proportion of Sample Exposed to Life Events During the Last 12 Months

Life Events	% of Sample
Death of first-degree relative	19%
Death of close family friend or relative	17%
Moving house or residence	8.4%
Serious illness or injury	6.7%
Something valuable lost or stolen	5.6%
Serious illness of close relative	5%
Break-up of steady relationship	3.9%
Serious problem with close friend, neighbour, or relative	3.4%
Unemployed or seeking job	2.8%
Sexual problems	1.7%
Problems with police or other authority	1.7%
Alcohol problems	1.1%
Problems with illegal drugs	1.1%
Laid off/sacked from work	1.1%
Major financial crisis	1.1%
Separation or divorce	0.6%
Retirement from work	0.6%
No. life events	
None	49.8%
1	29.7%
2	12.8%
>2	6.7%

TABLE 2. Proportion of Sample Exposed to Each Traumatic Experience During Life Span

Traumatic Experience	% of Sample
Learning of the sudden death or serious injury of a spouse, child, parent, close relative, or friend	51%
Being physically threatened, assaulted, or attacked	17.9%
Being in an accident that was life-threatening or resulted in serious injury	14.1%
Being tormented, terrified, stalked, or humiliated by someone repeatedly and Intentionally	10.3%
Having a life-threatening illness	8.3%
Witnessing someone being killed, maimed, or seriously injured	6.4%
Being sexually molested (someone touched or felt your genitals when you did not want them to)	4.5%
Being imprisoned or held captive	4.5%
Being in a natural disaster (fire, flood, earthquake, tornado) that was life-threatening or resulted in serious injury	3.8%
Accidentally causing serious injury or death to another person	3.2%
Surviving an attempted rape (someone tried to have sexual intercourse with you when you did not want to by threatening you or using force)	1.9%
Surviving a completed rape (someone had sexual intercourse with you when you did not want to by threatening you or using force)	1.3%
Being physically tortured by someone	0.8%
Being in military combat or a war zone	0%
No. traumatic experiences	
None	25%
1	31%
2	22%
>2	11%

Data Analysis

Firstly, a descriptive analysis of frequency and type of traumatic and life events was carried out. Comparative and correlational (when appropriate) analyses were then undertaken to assess possible associations between key demographic variables (gender, age, and level of ID) and our main study variables (ICD-10 disorders, traumatic experiences, and recent life events). Binary logistic regression was then used to see whether traumatic events and life events separately predicted the presence of ICD-10 disorders while controlling for possible confounding effects from other variables. Finally, binary logistic regression analyses were again performed, this time introducing both life events and traumatic experiences as predictors of ICD-10 disorders. The Statistical Package for Social Sciences (SPSS version 13.0) was employed for all the analyses.

RESULTS

As can be seen in Table 1, 75% of the participants had experienced at least 1 traumatic event during their life span, and 50% of the participants had experienced atleast 1 life event in the 12

months previous to the study (Table 2). Moreover, 38% of our participants presented ICD-10 disorders. Typology of these disorders is described in Table 3.

Table 4 presents the comparative analysis between our outcome variable (ICD-10 disorder) and key demographic variables (gender, age, and IQ scores). As can be seen, ICD-10 disorders were significantly more prevalent ($p < 0.5$) among our male participants. No other significant differences were found. The number of traumatic experiences and life events did not correlate significantly, nor present significant differences compared with any of the key demographic variables ($p < 0.5$).

Pearson correlation between traumatic experiences and life events was 0. 28 ($p < 0.01$), suggesting that there was a substantial amount of unshared variance between the 2 measures (92.2%).

Binary logistic regression results are presented in Table 5. Calculation of odds ratios (OR) showed that exposure to one or more traumatic experiences significantly increased the odds of a mental disorder (OR = 1.8; 95% CI = 1.2–2.5), as did exposure to life events (OR = 1.4; 95% CI = 1.1–2.0). In both cases, gender was introduced into the model to control for the differences in ICD-10 disorders between female and male participants (as shown in the bivariate analysis).

Finally, when both life events and traumatic experiences were entered together in the model, calculation of odds ratios revealed that traumatic experiences significantly increased the odds of ICD-10 disorders (OR = 1.7; 95% CI = 1.2–2.4) although life events were no longer significant (Table 6).

TABLE 3. Typology of ICD-10 Diagnosis

	Diagnosis	*n*	%
	No ICD-10 disorders	110	62%
	ICD–10 disorders	67	38%
F20–F29	Schizophrenia, schizotypal, and delusional disorders	16	24%
F30–F39	Mood [affective] disorders	21	31%
F40–F48	Neurotic, stress-related, and somatoform disorders[a]	21	31%
F50–F59	Behavioral syndromes associated with physiological disturbances and physical factors	4	6%
F84	Pervasive developmental disorders	5	8%

[a]Simple phobias were excluded due to their non-clinical relevance.

TABLE 4. Comparative Analysis Between Key Demographical Variables and Outcome Variables

	Presence of ICD-10 Disorder $N = 61$ (34%)	No Detected ICD-10 Disorder $N = 116$ (66%)	Statistical Significance
Age			
Mean (*SD*)	29.4 (5.7)	29.8 (7.1)	$t = 0.35$; $df = 175$ NS
Gender			
Male *n* (%)	51 (43.6%)	66 (56.4%)	
Female *n* (%)	16 (26.8%)	44 (73.2%)	$\chi^2 = 5.15$; $df = 1$*
IQ			
Mean (*SD*)	63.5 (12.2)	61.5 (10.3)	$t = 1.17$; $df = 121,3$; NS

NS indicates not significant.
*$p < 0.5$.

DISCUSSION

Though life events have been taken into account in the literature of ID, traumatic experiences have been largely ignored. The present data suggest that both life events and traumatic experiences were related to ICD-10 disorders in adults with ID. Nevertheless, when introduced together in a regression model, life events no longer seemed significant. This latter result indicates that traumatic experiences may be more important predictors of psychopathology than life events.

Our analysis also suggests that about one-third (34%) of our participants had an ICD-10 disorder. Epidemiological studies undertaken in Spain with analogous populations have shown similar rates of ICD-10 disorders (Salvador-Carulla et al., 2000). Considering the limitations often present when assessing rates of psychopathology in people with ID (Smiley, 2005), the present prevalence rates do not vary much from other point prevalence studies (Whitaker and Read, 2006). The same is true for the percentages of life events, where even the order in types of life events largely coincides with previous studies (Hastings et al., 2004). Nevertheless, regarding traumatic experiences across life span, absence of previous studies prevent us from making similar comparisons.

TABLE 5. Odds Ratios of Predictor Variables: Agreement Percentages

Variables	ICD-10 Disorder OR (95% CI)	Observed %	Estimated %		
			No ICD-10	Yes ICD-10	Correct %
Traumatic experiences	1.8 (1.2–2.5)*				
Gender	2.17 (1.1–1.5)**	No ICD-10	87	21	80.9
		Yes ICD-10	39	30	43.5
		Global %			66.0
Nagelkerke R^2	0.27				
Life events	1.4 (1.1–2.0)**				
Gender	2.3 (1.2–4.6)**	No ICD-10	103	8	92.8
		Yes ICD-10	54	12	18.2
		Global %			65.0
Nagelkerke R^2	0.07				

NS indicates not significant to the model.
*$p < 0.01$; **$p < 0.5$.

TABLE 6. Odds Ratios of Both Predictor Variables: Agreement Percentages

Variables	ICD-10 Disorder OR (95% CI)	Observed %	Estimated %		
			No ICD-10	Yes ICD-10	Correct %
Traumatic experiences	1.7 (1.2–2.4)*				
Life events	1.2 (0.8–1.7) NS	No ICD-10	89	17	83.0
Gender	2.2 (1.1–4.6)**	Yes ICD-10	43	28	39.3
Nagelkerke R^2	0.13	Global %			65.8

NS indicates not significant to the model.
*$p < 0.01$; **$p < 0.5$.

Among our participants, 75% had experienced at least 1 traumatic life event during their life span. It should be also noted that 51% of the traumatic experiences were related to the "learning of the sudden death or serious injury of a spouse, child, parent, close relative, or friend." Interestingly, age did not correlate significantly with the number of traumatic events. As traumatic experiences were assessed for the whole life span, it would have been expected that the higher the age, the higher the number of traumatic events. This finding may suggest that the incidence of traumatic experiences probably does not increase significantly after adulthood is reached in this particular population.

Regarding the regression analysis, consistent with general findings from previous research, exposure to one or more life events in the 12 months before the study increased the odds of ICD-10 disorders. No further analysis regarding the types of life events or the types of disorders could be undertaken, because of the small number of participants corresponding to each subgroup, which was also the case for traumatic events.

Finally, when both life events and traumatic events were introduced together in the regression model, life events were not retained as a significant predictor. As already stated, conclusions drawn by these findings must be interpreted cautiously: they can be due to the difference in the lifespan taken into account (12 months vs. whole life span) or, possibly, measures can be overlapping each other. In this case, problems with multicolinearity should be ruled out, because these exist when the absolute value of the coefficient of correlation between 2 variables exceeds $r = 0.5$ (Coulombe et al., 2005). Therefore, we can come to at least 2 conclusions: (1) "stressing events" over the life span are more related to ICD-10 disorders than events happening just 12 months before; (2) though possibly overlapping measures, the unshared variance of traumatic events is a better predictor of ICD-10 disorders than that of life events.

Some methodological limitations should also be addressed. To take into account potential lack of understanding and difficulties in communication, checklists were administered to key informants who knew the client well, as suggested by Nadarajah et al. (1995). However, nondisclosed events may have therefore been overlooked. In addition, some studies have also noted associations between life events and subgroups of participants with ID (e.g. high-functioning people with Down syndrome, autism, etc.) regarding the outcome of mental illness, thus illustrating that, perhaps, global approaches such as ours could hide possible effects (Nadarajah et al., 1995; Hamilton et al., 2005). Furthermore, our participants only present mild and moderate ranges of ID, and therefore these conclusions may not be generalized to other groups with more severe ID. Also relevant to our participants is the fact that the study took place in just one setting, limiting the generalisability of the present results. Prospective designs are needed to identify possible casual relations more clearly.

In summary, future research should probably focus on traumatic experiences in people with ID. Conceptually important differences should be taken into account when considering preventive interventions. In a diathesis model, traumatic experiences across life span would count as predisposing factors, whereas life events would be precipitating ones. This is particularly important, as it is generally accepted that prevention should take place when predisposing factors are present, not just in the presence of precipitating ones.

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7. De dentro a fuera. La familia.

7. De dentro a fuera. La familia.

Las personas con discapacidad intelectual, y más en sociedades de cultura latina, configuran un sistema tan interdependiente que dicha influencia mutua no puede ser pasada por alto si queremos entender en profundidad los problemas de salud mental de las personas con discapacidad intelectual.

De ahí que nos propusiéramos, congruentemente con la visión holística que pretendíamos abordar, acercarnos a entender el papel de las familias y su relación con las enfermedades mentales de las personas con discapacidad intelectual. Como ya estableciera Orsmond et al., 2003, se trata de una relación circular, en la que el estado de la persona con discapacidad intelectual influye sobre la familia, y el estado de la familia sobre el de la persona con discapacidad intelectual.

Con el estudio *Family impact in individuals with intellectual disability, mental health disorders and dual diagnosis. A comparison*, pretendíamos dar un paso más en la comprensión de esta interrelación al desgranar cada acción discapacitante y analizarla por separado en su influencia en la familia.

7.1. Validación en población española de la entrevista de carga familiar objetiva y subjetiva (ECFOS-II) en familiares de pacientes con esquizofrenia.

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Validation in Spanish population of the family objective and subjective burden interview (ECFOS-II) for relatives of patiens with schizophrenia

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[8] PSICOST-RED RIRAG scientific group is a multidisciplinary team made up of psychiatrists, psychologysts, social care workers, nurses, statisticians and economists, whose objective is the standardize evaluation of services and expenses of chronic mental patients

Introduction. The family burden experienced by caregivers of people with schizophrenia is one of the most relevant consequences of this disorder. This paper aims to show the validity and reliability of the Spanish version of the Family Burden Interview Schedule (FBIS) designed to assess objective and subjective family burden for people with schizophrenia.

Method. Design: cross sectional study. Participants: 356 patients fulfilling DSM-IV criteria for schizophrenia from four Spanish geographic areas (Barcelona, Madrid, Pamplona and Granada) and 205 main caregivers of these patients were assessed. Material: caregivers were assessed with the Family Burden Interview Schedule (FBIS) Spanish version (ECFOS-II), which assesses family burden in eight different modules: activities of daily living, disrupted behaviors restraint, expenses, caregiver's routine, concern, help, repercussions on health, and assessment of general burden. Patients were also assessed with PANSS, DAS-sv and GAF. Statistical analysis: in order to assess internal consistency, parametrical tests of Cronbach's alpha were undertaken. To compute test-retest reliability Cohen's kappa and Weighted kappa were used. A principal component analysis was undertaken for assessing construct validity. Convergent validity was assessed with Spearman and Pearson correlation coefficients respectively, relating the instrument with the psychopathological (PANSS) and disability scale (DAS-sv) and general functioning (GAF). Moreover, a description of the viability of the ECFOS-II was described by a questionnaire especially designed for this purpose.

Results. Cronbach's alpha coefficient was 0.85 for the global assessment. Test-retest coefficients were very high, both for Cohen's kappa and for Weighted kappa, most values being between 0.61 and 1. Principal component analysis detected four factors that coincide with the modules of the original schedule. In the convergent validity we found that these factors are related with the symptom, disability and global functioning characteristics of the patients.

Conclusions. ECFOS-II results in a valid and reliable instrument for assessing family burden experienced by caregivers of people with schizophrenia.

Key words:
Schizophrenia. Family burden. Validity. Reliability.

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Validación en población española de la entrevista de carga familiar objetiva y subjetiva (ECFOS-II) en familiares de pacientes con esquizofrenia

Introducción. La carga familiar experimentada por los cuidadores de personas afectas de esquizofrenia constituye una de las consecuencias más relevantes del trastorno. Debido a esto se ha llevado a cabo la validación de la versión castellana del instrumento *Family Burden Interview Schedule* (FBIS) de carga familiar objetiva y subjetiva para personas con esquizofrenia.

Método. Diseño: estudio de corte transversal. Participantes: se evaluaron 356 pacientes con diagnóstico DSM-IV de esquizofrenia de cuatro áreas geográficas españolas (Barcelona, Madrid, Pamplona y Granada) y 205 cuidadores principales de estos pacientes. Material: Entrevista de Carga Objetiva y Subjetiva ECFOS-II, que mide la carga familiar en ocho módulos distintos: actividades de la vida cotidiana, contención, comportamientos alterados, gastos, rutina del cuidador, preocupación, ayuda, repercusión en la salud y evaluación del nivel de carga global. Además se evaluaron a los pacientes con la PANSS, la DAS-sv y el EEAG. Análisis estadístico: para evaluar la consistencia interna se utilizaron las pruebas paramétricas de alfa de Cronbach. Para el cálculo de la fiabilidad test-retest se utilizó el coeficiente kappa de Cohen y el kappa ponderado. Se realizó

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un análisis de componentes principales con el fin valorar la validez de constructo. Asimismo, la validación convergente fue evaluada con el coeficiente de correlación de Spearman y de Pearson, relacionando el instrumento con escalas psicopatológicas (PANSS), de discapacidad (DAS-sv) y de funcionamiento general (EEAG). Por último, se describió la viabilidad del ECFOS-II a través de un cuestionario elaborado al efecto.

Resultados. Los coeficientes de alfa de Cronbach fueron de 0,85 para la entrevista global. Los coeficientes estudiados para la fiabilidad test-retest fueron muy altos, tanto para el kappa de Cohen como para el kappa ponderado, situándose los valores en la mayoría de los casos entre 0,61 y 1. El análisis de componentes principales detectó cuatro factores que coinciden con los módulos del cuestionario original. En la evaluación de la validez convergente encontramos que estos factores están relacionados con las características sintomatológicas, de discapacidad y de funcionamiento general del paciente.

Conclusiones. El ECFOS-II se muestra como un instrumento válido y fiable en su versión castellana para evaluar la carga familiar existente en los cuidadores de personas con esquizofrenia.

Palabras clave:
Esquizofrenia. Carga familiar. Validez. Fiabilidad.

INTRODUCTION

The development of community psychiatry entailed the progressive deinstitutionalization of persons with mental disease who had been previously committed. The consequence of this process is that many families have had to deal with the obligations entailed in the care of an ill family member. Based on this change, the interest in the evaluation is focused on verifying not only the effects that living in the community has on the patients but also in studying the effects that their care has on the family members in charge of them[1-8].

Family burden or impact is associated to characteristics of both the patients and caregivers[9-12]. According to Hoenig and Hamilton, family burden can be broken down into objective and subjective dimension. Objective family burden refers to the observable and quantifiable consequences derived from the patient care while subjective family burden refers to the evaluations that the caregiver makes of his/her situation and degree in which he/she perceives it as overwhelming. It is generally accepted that greater objective burden is related with greater number of disruptive behaviors, with the fact of living with the patient and with less likelihood of obtained help to care for the patient. Furthermore, greater subjective burden is related with greater presence of symptoms in the patient and with the perception of less competence by the caregiver to take charge of his/her care[13-15].

There are few instruments that evaluate family burden of persons with schizophrenia. Those that are used most are Social Behaviour Assessment Schedule (SBAS)[16,17], Experience of Caregiving Inventory (ECI)[18], Involvement Evaluation Questionnaire (IEQ)[19] and The Family Burden Interview Schedule-Short Form (FBIS-SF)[20].

The only one of these that is validated to Spanish is the IEQ, in its European version done by the EPSILON group. The IEQ is made up of 5 subscales (tension, supervision, worrying, urging and other non-included items) made up of a total of 33 items. This questionnaire measures family burden, considering the objective dimension, that is, evaluating the frequencies of behavior of help or the worrying of the family member. However, it does not measure worrying that generates these behaviors nor the positive aspects of the family burden. It also does not evaluate the expenses generated by these cares.

SBAS and ECI stand out among the instruments on family burden that have not been validated in Spanish. The former is a semi-structured interview designed to evaluate the effect of the subject's behavior on his family members and the stress that this produces in the informer through seven different sections, but it does not make it possible to obtain global scores. The ECI, on the contrary, is a self-administered instrument that tries to examine the evaluation made by the caregiver on the positive and negative aspects of the experience of caring for a person with a mental disorder through 66 items, but it also has not been validated.

None of these scales analyze aspects such as the help the informer has or the repercussions that the disease of their family member has had on their health. They do not quantify the hours of dedication invested nor do they permit the clinician or caregiver to make a global assessment of the positive and negative effects derived from the care of a person with a mental disorder.

Most of the limitations of the previous instruments are corrected with the FBIS-SF. This is a hetero- or self-administered interview with an approximate duration of 30 minutes that is aimed at the first-degree relatives of persons whose ages are between 18 and 64 years affected by a severe mental disorder and who live with the caregivers. This instrument includes 5 modules related with the negative aspects derived from the care of a person with a mental disorder. These modules may be used and interpreted independently since there is a global score for each one of them. Furthermore, the expenses derived from the family burden can be measured.

Thus, the objective of this study is to adapt and validate the FBIS-SF scale to Spanish (ECFOS-II) and to analyze its utility as a measurement instrument of the family burden or impact experienced by relatives of persons with the diagnosis of schizophrenia.

METHODOLOGY

Development and description of the objective and Subjective Family Burden Interview

The ECFOS-II interview was developed from the Spanish translation of The Family Burden Interview Schedule-Short Form (FBIS-SF). Three mental health care professionals made an independent translation of the original. Then the investigator team agreed on a final one based on the three versions, which was backtranslated. This inverse translation confirmed the adaptation of the translation of the interview with the original. After, the translated version of the FBIS-SF was administered to 40 relatives of patients with schizophrenia belonging to the participating sites of the regional communities of Madrid, Catalonia, Navarra and Andalusia. Based on this analysis of the understanding of the items and the feasibility of administration, the expert's committee who developed the instrument decided to introduce and modify some items. Four modules were added to the original interview in order to cover certain aspects that had been absent up to then and that should be taken into account when evaluating the burden experienced by the principal caregivers of persons with schizophrenia. In order to evaluate if these items were easy to understand, some relatives were reevaluated. Table 1 collects the questions of the original scale (FBIS-SF) and the modifications (ECFOS-II).

ECFOS-II is a self- or hetero-administered interview that takes approximately half an hour. Its application scope is that of the principal caregivers of persons with schizophrenia who live in the community. The interview is made up of an introductory section in which the sociodemographic aspects are collected and by different modules that evaluate the dimensions of family burden: the help provided in the activities of the daily life of the patient, the restraint made of the altered behaviors, a list of financial expenses; impact on the life of the caregiver, reasons of concerns by the patients, help available, effects perceived on health and global repercussions experienced individually and by the family. Each one of these modules are evaluated with dichtomic answers or by Likert like scales that range from 4 to 5 points. The complete ECFOS-II interview can be obtained from the authors through the web page: www.rirag.com .

Participants

A sample of patients with a DSM-IV diagnosis of Schizophrenia whose ages were between 18 and 65 years who had been attended in 4 Community Mental Health Sites of the areas of Barcelona (Gavà Mental Health Care Site [MHCS]), Madrid (Salamanca MHCS), Granada (MHCS La Loja) and Navarra (MHCS Burlada) were selected. These areas were selected because they were representative of different socioeconomic contexts and because they differed in both availability and organization of the mental health care services. Based on the existing records in each one of these centers, a total of 356 patients were randomly selected. Of these, only 205 relatives could be interviewed due to the refusal of the patient, caregiver or therapist (n = 93), to the absence of the caregiver (n = 18), because the patient was independent (n = 10) or for other reasons (n = 30). Once the appropriate interviews were made with the patients and their consent had been obtained, the principal caregivers were contacted in order to administer the ECFOS–II interview.

Evaluation instrument

In addition to the ECFOS-II scale, in the caregivers, discapacity, functioning and symptoms of the patients receiving the cares were collected.

The patients were evaluated with the following questionnaires:

- The Negative Syndrome Scale for schizophrenia (PANSS) of Kay (1986)[21] translated and validated by Cuesta and Peralta (1994)[22], that evaluated symptoms in: positive, negative and general symptoms.
- The Global Assessment of Functioning Scale (GAF) (Endicott, 1976)[23] translated and validated to Spanish in the DSM-IV (1995)[24]. This scale assesses global functioning on the clinical and social level, indicating better functioning with better score.
- The Disability Assessment Scale, short version (DAS-sv) (ICD-10, 1992)[25], evaluates more disability at greater score in: personal care, occupation level, family relationships and other social relationships.

Statistical analysis

Design of validity and reliability study.

In regards to the reliability analyses, assessment of the homogeneity of the interview items (internal consistency) was made by calculation of their correlation with the total using Cronbach's alpha coefficient. Furthermore, the relationship between the objective and subjective burden questions included in some of the modules was assessed with Spearman's correlation coefficient.

For the test-retest reliability calculation, two different types of statistical tests were used based on reply alternatives. For the dichotomic reply items, the kappa index was applied while for those have multiple replies, weighted Kappa index was used with weights in most of the cases of 1, 0.75, 0.5, 0.25 and 0 except on two occasions in which the weight was 1, 0.5 and 0 because the subjects only answered 3 of the 5 reply alternatives and on one occasion the weight was 1, 0.67, 0.33 and 0 due to the same situation but with

Table 1 Description of FBIS/SF and the ECFOS-II

FBIS/SF	ECFOS-II
Care in daily life activities	**Care in daily life activities**
For each item:	For each item:
Help provided in the last 30 days	Absence/presence of need for help
Concern in relationship to the help given	Help provided in the last 30 days
Supervision module	Concern in relationship to help given
For each item:	Hours dedicated to care in the daily life activities
Control of altered behaviors in the last 30 days	**Restraint of altered behaviors**
Concern in relationship to these behaviors	For each item:
Financial expenses module	Control of altered behaviors in the last 30 days
Absence/presence of financial expenses related with 11 activities in the last month	Concern in relationship to these behaviors
Amount of money provided in each activity	General:
Subjective evaluation of financial burden in the last year	Hours of dedications to the restraint of altered behaviors
Impact in daily routine module	**Financial expenses module**
Impact perceived in one's own life	Absence/presence of financial expenses in the last month
Worrie	Absence/presence of expenses in 16 activities in the last month
Concern experienced in 7 different areas	Mount of money provided for each activity
	Subjective evaluation of financial burden in the last year
	Money provided by the patient's family member to the family economy
	Changes in caregiver's daily routine
	Impact perceived in one's own life
	Reasons for concern by the patient
	Concern experiences in seven different areas
	Help the informer has
	Absence/presence of help available
	Hours of help received in the week
	Repercussion in the caregiver's health
	Use/non-use of health care services
	Number of visits made
	Medication prescribed (dose and days)
	Days of sick leave
	Global evaluation of the informer
	Absence/presence of repercussion on the informer
	Absence/presence of negative repercussion objective and subjective negative effect
	Absence/presence of positive repercussion
	Global evaluation of evaluator
	Absence/presence of repercussion on the informer
	Absence/presence of negative repercussion objective and subjective negative effect
	Absence/presence of positive repercussion

different Likert scale items. The values of this coefficient were interpreted following the Feinstein proposal[26] so that kappa values lower than 0 meant a poor agreement level, from 0 to 0.20 low, from 0.21 to 0.40 fair, from 0.41 to 0.60 moderate, from 0.61 to 0.80 strong and from 0.81 to 1.00 almost perfect. Kappa values were not calculated in the cases of questions with positive replies with low prevalence due to their null utility[27,28].

To verify the validity of the scale, the construct validity was analyzed by an analysis of principal components, in which each one of the questions of the original questionnaire on assessment of family burden were included. The screening questions, excluding those referring to subjective or objective burden, were included in the analysis. The lists of expenses (module C) and questions related with global subjective and objective burden were also excluded. Extraction of four factors was done, as long as they explained more than 1 in the eigenvalue.

The convergent validity was tested with Spearman's correlation between the totals of the ECFOS II and DAS scales and with Pearson's correlations for the relationship between the data for ECFOS-II and GAF and PANSS.

Finally, applicability was assessed from the percentages obtained in the viability questionnaire administered to the interviewers who evaluated time used in the conduction of the interviews, need, sufficiency, understanding and acceptance of the questions, quality of information collection of the instrument and global fatigue of the person interviewed. A valid percentage was considered to exist when 70 % of the replies given were between a lot and much.

The statistical programs used were the Statistical Package for Social Sciences, version 12,0[29] and the Stata Statistical Software: version 8.0[30].

RESULTS

Description of the informal caregiver sample (relatives)

Of the 205 caregivers interviewed, 21.5 % (n = 44) came from Barcelona, 22.4 % (n = 46) from Granada, 28.3 % (n = 58) from Madrid and 27.8 % (n = 57) from Navarra. Of these, 163 were women and 42 men with a mean age at 58.66 years. Most of them had completed a minimum of primary studies (85.9 %), did not work outside of the home (65.4 %), were parents of the patients they were caring for (63.4 %), lived with them (77.6 %), spent more than 4 hours daily with them (70.7 %) and reported that they had a good or very good relationship with the patients (69.7 %) (table 2).

Table 2 Sociodemographic characteristics of the principal caregivers and type of relationship that they maintain with the patients

	N (%)
Mean age	58.66 (SD: 14.63)
Gender	
Men	42 (20.5)
Women	163 (79.5)
Level of studies	
No schooling	29 (14.1)
Schooling	176 (85.9)
Work situation	
Full time work	41 (20)
Part time work	30 (14.6)
Does not work outside the home	134 (65.4)
Relationship with the patient	
Husband/wife	22 (10.7)
Father/mother	130 (63.4)
Son/daughter	5 (2.4)
Brother/sister	38 (18.5)
Friend	1 (0.5)
Other	9 (4.4)
Lives with patient	
Yes	159 (77.6)
No	46 (22.4)
Degree of relationship with the patient	
Less than 1 hour/week	2 (1)
1-4 hours/week	17 (8.3)
5-7 hours/week	7 (3.4)
8-14 hours/week	6 (2.9)
15-21 hours/week	8 (3.9)
22-28 hours/week	20 (9.8)
> 28 hours/week	145 (70.7)
Quality of relationship with the patient (perspective of the caregiver)	
Very good	55 (26,8)
Good	88 (42,9)
Normal	29 (14,1)
Fair	29 (14,1)
Bad	3 (1,5)
Very bad	1 (0,5)

Description of the patient sample.

The initial sample was made up of 356 patients, but family burden was only evaluated in 205 of them. Of the subjects interviewed, 71.6 % were men with a mean age at 37.97 years (SD: 10.27). It was observed that most of them (75.6 %) were single, lived with their origin family (69.8 %), had primary education level (50 %) and were pensioners (70.4 %). There were no statistically significant differences between the subjects whose relatives were interviewed and those in which they were not interviewed in regards to gender, age and psychopathology. The only different variable was the positive PANSS in which the subjects whose relatives could not be interviewed had a greater total score (p = 0.035).

Reliability of ECFOS-II interview

Internal consistency

Table 3 shows the results of the internal consistency through Cronbach's alpha coefficient for the global interview. Spearman's correlation between the items that evaluate the objective and subjective burden in 4 of the modules existing in the interview is also presented. As can be observed, the items of ECFOS-II had a high homogeneity between them (Cronbach's alpha coefficient = 0.85) and the correlations between the objective and subjective burden are also elevated (0.7–0.94), also confirming the internal consistency of the test.

Table 3 **Internal consistency of ECFOS-II and correlation between objective and subjective burden items present in four of the ECFOS-II modules**

Internal consistency of ECFOS–II	Cronbach's alpha
	0.85
Correlation between objective/subjective subjective burden in modules	**Spearman's correlation**
Daily life activities	
Personal cleanliness	0.89
Medication	0.77
Housework	0.79
Shopping	0.81
Family routine	0.75
Means of transportation	0.79
Financial administration	0.78
Organization of time	0.84
Attendance to consultations	0.83
Administrative formalities	0.86
Restraint altered behaviors	
Embarrassing behaviors	0.90
Demands for attention	0.94
Nighttime trouble	0.93
Heteroaggresivity	0.92
Self-aggressivity	0.91
Alcohol abuse	0.92
Drug abuse	0.87
Assessment of global burden (informer)	
Negative burden on informer	0.72
Negative burden on family	0.81
Assessment of global burden (professional)	
Negative burden on informer	0.79
Negative burden on family	0.81

Test-retest reliability

The test-retest reliability values of the interview are shown in table 4. As we can observe, in the module on care in the activities of daily life, in that of supervision of altered behaviors and in that of evaluation of global family burden by the interviewer, the agreement level was moderate to almost perfect, except in the item referring to time organization in which it was fair. In the financial expenses and help modules that we have for the informer, almost perfect agreement levels were obtained while in the modules on the impact on the life of the caregiver and Concern and global evaluation of family burden by the informer, there was more variability. In regards to the first one, we obtained a moderate agreement level in the only item that we could evaluate regarding impact on the social life of the caregiver. In the second one, the most frequent agreement levels were between moderate to strong, less in the item regarding treatment prescribed to the patient in which the weighted kappa value was 0.04. Finally, in the previously mentioned third module, the levels range from fair to almost perfect.

Validity of the ECFOS–II interview

Construct validity

The results of the analysis of principal components are shown in table 5. We found that four factors explain almost 50% of the variance, all of them with an eigenvalue greater than 1.5. Furthermore, as can be observed, the factors obtained adjust to the initial modules of the interview.

In factor 1, the only item that is higher in the supervision factor is housework, even though it has considerable weight in factor 1. In the concern factor, all the items adapt in the same way as in the original scale. In factor 3 of impact of caregiver activities, only the item referring to missing work that has more weight in the supervision factor remains outside. Finally, factor 4 refers to supervision and the only item that also has a weight in other factors would be alcohol, although its saturation is adequate in factor 4. These results indicate a high coincidence between the original modules and the statistical factors found.

Convergent validity

Convergent validity based on the relationship between the family burden factors obtained and the clinical characteristics of the patients in the sample is shown in table 6. We have found that the factor that refers to care in daily activities is related with the subscales of psychopathology and general functioning.

Table 4 Test-retest reliability with Cohen's Kappa values for the objective and subjective family burden interview modules applied to 205 principal caregivers (ECFOS-II)

ECFOS-II	Cohen's Kappa
Daily life activities care module	
Personal cleanliness	0.69
Medication	1.00
Housework	0.52
Shopping	0.63
Family routine	0.48
Transportation	1.00
Financial administration	0.69
Organization of time	0.22
Attendance to consultations	*
Administrative steps	0.53
Altered behaviors supervision module	
Embarrassing behaviors	0.87
Demands for attention	0.46
Nighttime trouble	1.00
Heteroaggresivity	*
Self-aggressivity	1.00
Alcohol abuse	1.00
Drug abuse	1.00
Financial expenses module	**1.00**
impact of caregiver's live module	
Work	*
Social life	0.53
Domestic work	**
Care to other family members	**
Concern module	
Physical integrity	0.52
Treatment	0.04
Social life	0.59
Physical health	0.64
Daily life	0.50
Money	0.60
Family future	0.68
Help available module	**0.88**
Repercussions on caregiver's health module	*
Global assessment of informer's module	
Presence of burden on informer	0.70
Negative burden on informer	0.60
Positive effect on informer	0.35
Presence of burden on family	0.40
Negative burden on family	0.81
Positive effect on family	0.24
Global assessment of interviewer module	
Presence of burden on informer	0.74
Negative burden on informer	0.58
Positive effect on informer	0.69
Presence of burden on family	0.77
Negative burden on family	0.89
Positive effect on family	0.57

*Reliability not calculated because one of the variables studied was a constant.
**Kappa values of 0 due to inconsistency of reply of one or two subjects.

Table 5 Analysis of principal components of the Objective and Subjective Family Burden Interview Items (ECFOS-II)

Family burden items	Factors			
	I	II	III	IV
Care in daily life activities (eigenvalue: 7.1; % of total variance: 25.1)				
Personal cleanliness	0.627			
Medication	0.563			−0.293
Housework	0.439	0.489		−0.210
Shopping	0.562	0.288		−0.215
Means	0.277			−0.214
Transportation	0.753			
Money	0.525	0.332		
Schedules	0.553			−0.295
Consultation	0.666			
Formalities	0.747		0.213	
Concerns (eigenvalue: 2.8; % of total variance: 10.1)				
Safety		0.725		
Type of treatment		0.402	0.389	−0.288
Social life		0.618	0.365	
Physical health		0.565	0.271	−0.282
Daily life		0.814		
Handling of money	0.202	0.723		
Future	0.210	0.658		
Impact on daily activities (eigenvalue: 1.9; % of total variance: 6.7)				
Absences at work				−0.592
Leisure plans		0.241	0.750	
Housework		0.287	0.797	
Time of family		0.235	0.792	
Supervision (eigenvalue: 1.7; % of total variance: 6.1)				
Rare behavior	−0.260			0.553
Calling attention			−0.311	0.528
Bothering	−0.278		−0.233	0.504
Heteroaggression	-0.280			0.643
Self-aggression	-0.378			0.402
Alcohol		-0.368	0.433	0.380
Drugs		-0.243		0.472

Extraction method: analysis of principal components. The burdens greater than 0.20 are presented.

The concern factor is also related with psychopathology, functioning and discapacity. The impact factor in the activities of the caregiver is only related with discapacity in per-

Table 6 Pearson's and Spearman's correlations between Factors of Analysis of Principal Components of the Objective and Subjective Family Burden Scale (ECFOS-II) and the Positive and Negative Syndromes Scale of Schizophrenia (PANSS), Global Assessment of Functioning Scale (GAF) and Disability Assessment Scale of the WHO (DAS-sv)

	Assistance in daily life activities	Concern	Impact on daily activities	Supervision
Positive PANSS	0.14	0.24***	0.07	–0.31****
Negative PANSS	0.32****	0.07	–0.13	–0.02
General PANSS	0.24***	0.29****	0.078	–0.18*
Personal care DAS	0.37****	0.24***	0.21**	–0.12
Occupational functioning DAS	0.37****	0.11	0.01	–0.10
Family functioning DAS	0.29****	0.29****	0.15	–0.09
DAS in other activities	0.23***	0.17*	0.073	0.04
GAF	–0.41****	–0.18**	–0.08	–0.01

*$p < 0.05$; **$p < 0.01$; ***$p < 0.005$; ****$p < 0.001$.

sonal care. Finally, the supervision factor is related with psychopathology.

Viability of the interview

In regards to viability, we observe that the interview was positively evaluated by the professionals, who mostly considered that the questions included in the instrument were necessary, sufficient, good information coders and easy to understand as well as being well accepted by the person being interviewed (table 7).

DISCUSSION

The objective and subjective family burden interview (ECFOS-II) is a valid and reliable instrument to evaluate family burden presented by the relatives of persons having schizophrenia. As far as we know, it is the only scale validated to Spanish that makes it possible to evaluate family burden, including subjective and objective dimensions of this concept as well as the expenses that would be generated in this type of care.

Analysis of the internal consistency demonstrated high homogeneity between all the items of the interview and the test-retest demonstrated high stability in the replies over time.

The analysis of principal components made confirms the existence of the 4 most significant modules of the interview designed by the original authors: care in daily at committees, supervision, impact in daily activities of caregiver and concerns. As they propose, in order to make the total score of each module, it is necessary to divide the sum of each one of the scores obtained in each item and the number of items of the module[19]. However, the cutoff points have still not been defined on the micro- (in each one of the modules) and macro-level (in all the interview) that would make it possible to decide when a person has a family burden or not.

Therefore, we believe that the ECFOS-II may be useful on the clinical level as well as on the research one since, in the beginning, it would make it possible to analyze the situation in which the principal caregivers of the persons suffering schizophrenia are found in a relatively short period of time. This general description would allow us to make a subsequent design and application of intervention strategies aimed at both the family and the patient (psychoeducation, training in communication skills and problem solving, etc.) in order to improve their situation and quality of life.

On the other hand, and considering the new Dependence Law that will enter into force soon in our country, we think that an instrument such as this one is even more interesting if possible when analyzing the situation of these persons who need help from the family.

One limitation that should be taken into account is that we have not been able to evaluate the reliability existing in the items of some of the modules because there were variables that were a constant and because of the reduced size of the sample used. The low prevalence of positive reply of some items also made it impossible to calculate the kappa value in some cases.

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Table 7 Percentage of replies given by caregivers in each one of the items evaluated by the viability questionnaire

Viability questionnaire of the ECFOS-II	N (%)
Are the questions included in the instrument necessary?	
Not at all	1 (0.5)
Little	14 (6.9)
Enough	141 (69.1)
Much	48 (23.5)
Are the questions included in the instrument sufficient?	
Not at all	0 (0)
Little	12 (5.9)
Enough	97 (47.5)
Much	95 (46.6)
Does the instrument adequately collect the information?	
Not at all	0 (0)
Little	17 (8.3)
Enough	93 (45.6)
Much	94 (46.1)
Does the person interviewed understand the questions well?	
Not at all	2 (1)
Little	45 (22.1)
Enough	94 (46.1)
Much	63 (30.9)
Does the person interviewed accept the questions well?	
Not at all	1 (0.5)
Little	22 (10.8)
Enough	84 (41.2)
Much	97 (47.5)
Does the person interviewed become tired during the interview?	
Not at all	63 (30.9)
Little	97 (47.5)
Enough	23 (11.3)
Much	21 (10.3)

Network of Results applied to Management in Incapacity and Mental Health (Red de Investigación de Resultados Aplicados a la Gestión en Discapacidad y Salud Mental) (RIRAG) (G03/061) and the Spanish Ministry of Health, Instituto de Salud Carlos III, RETICS RD06/0011 (REM-TAP Network).

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7.2. Validation of the Subjective and Objective Family Burden Interview (SOFBI/ECFOS) in primary caregivers to adults with intellectual disabilities living in the community.

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Validation of the Subjective and Objective Family Burden Interview (SOFBI/ECFOS) in primary caregivers to adults with intellectual disabilities living in the community

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Abstract

Background There is little information on the psychometric properties of instruments for assessing family care burden in adults with intellectual disabilities (ID). The aim of this study is therefore to analyse the usefulness of the 'Subjective and Objective Family Burden Interview' (SOFBI) in the assessment of principal caregivers in Spain.
Methods The SOFBI was administered to 166 principal caregivers of adults with ID in a vocational centre. The psychometric analysis included: internal consistency, inter-rater and test–retest reliability, construct validity, convergent validity with the World Health Organization's Disability Assessment Schedule II, and feasibility.
Results The Cronbach's alpha was 0.88 for the overall interview and always above 0.7 in the quantitative subdomains. The Kappa coefficients for test–retest were between 0.5 and 0.8, whereas inter-rater agreement was nearly perfect. Maximum-likelihood factor analysis showed four well-defined factors, which fitted the previously designed domains. Feasibility was also good.
Conclusions The SOFBI is a multi-domain, modular instrument which is feasible, reliable and valid for measuring the burden of family caregivers to adults with ID living in the community.

Keywords burden of care, families, intellectual disabilities, interview, validation

Background

There is an increasing interest on the well-being of families with persons with intellectual disabilities (PWID), including research on quality of life, cultural differences, parenting education, parenting stress, caregiving demands and needs, family support and satisfaction (Sobsey & Calder 2006). However, less attention has been paid to the assessment of family burden or impact in relatives of adults with intellectual disabilities (ID) living in the community. The available studies concentrate mainly in other settings, in other age segments or in

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specific domains related to the burden construct. For example, a number of studies have explored formal caregivers' burden in residential settings (McCarron *et al.* 2002, 2005) or in families with children with ID (Thyen *et al.* 2003). The subjective burden has been analysed in ageing family carers to PWID using the Zarit Burden Interview (Greenberg *et al.* 1997), or in families of children with ID using the Nijmegen Family Situations Questionnaire (Maes *et al.* 2003). Stress related to caregiving has been measured by a significant number of instruments, including the Questionnaire on Resources and Stress Friedrich short form (White & Hastings 2004), the Caregiver Strain Index (Luescher *et al.* 1999), or the Family Stress and Coping Interview (Nachshen *et al.* 2003). In spite of that, the available information on instruments for assessing family burden in ID is largely insufficient, particularly with regard to their psychometric properties, such as feasibility, reliability and validity, as well as to their conceptual framework. Family burden is a complex, multidimensional construct with both subjective and objective components (Hoenig & Hamilton 1966; Schene 1990). Therefore, instruments exploring burden related to specific activities of daily living (ADLs) and to supervision of behavioural problems should be available. They should also incorporate the positive aspects of caring for a person with ID, which may offset the objective burden of care under favourable circumstances. As well, they should provide information on the objective aspects of care such as frequency and hours of care related to ADLs, and oversight on behavioural problems should be recorded in order to enable cost analysis and related burden studies. Finally, instruments should also facilitate comparisons with informal caregiving in other health conditions, and eventually, it should prove its equivalence and generalizability to other cultural environments and countries.

The assessment of the psychometric properties of family burden instruments is particularly important in Spanish-speaking countries, where there are barely any studies analysing the situation of families with PWID. In Spain, 75% of adults with ID live with their families, while only 25% live in other residential settings (Consejería de Familia y Asuntos Sociales 2004). This represents a high rate of PWID living at home in comparison with other countries for which data are available (May & Hogg 2000), and is in accordance with the well-stated fact that, in the USA, Hispanic families show the lowest rate of use of residential facilities for PWID, tending to keep the PWID at home (Lakin *et al.* 2004).

For all the above, the purpose of the present study is to test and explore the psychometric properties of an interview for assessing the burden of primary caregivers to adults with ID living in the community: the Subjective and Objective Family Burden Interview (SOFBI/ECFOS), in its Spanish version.

Method

This study was conducted at the Pardo-Valcarce Foundation for PWID, in cooperation with the Universidad Autónoma of Madrid and the PSICOST research thematic network on outcome management in mental health and disabilities. PSICOST is a Spanish research association on costs and burden of neural disorders and disabilities linked to the Mental Health Economics European Network (MHEEN). Pardo-Valcarce Foundation provides community care services for over 450 persons with developmental disabilities in Madrid (Spain), including educational, vocational and labour services, as well as specialized care for persons with psychiatric disorders and ID.

Participants

The participants were principal caregivers to adults aged above 17 years at the Pardo-Valcarce Vocational Centre for PWID. The initial number of participants comprised 171 principal caregivers, out of whom 166 were finally interviewed, because five caregivers refused to participate. The caregiver's average age was 58 years (SD = 8.9), 88% of them were women (n = 146) and 12% men (n = 20). The mother was the primary caregiver in 82% of the cases (n = 136), the father in 12% (n = 30), and the remaining 6% were sisters (n = 6) and maternal aunts (n = 4). Regarding their educational level, 53% (n = 88) had less than 7 years of education, 25% had finished primary school (n = 41), 15% had graduated from secondary school (n = 25), and 7% had at least started university studies (n = 12). The participants with ID had an average age of 29 years (SD = 6.9); 36% of them were women (n = 59) and

64% men ($n = 107$). As to their level of ID, 54% ($n = 90$) presented mild ID (IQ 50–69; WHO 1993), and the remaining 46% ($n = 76$) had moderate ID (IQ 35–49; WHO 1993), all assessed through the Wechsler Adult Intelligence Scale-III (WAIS-III) (Wechsler & Kaufman 1998).

Materials

Subjective and Objective Family Burden Interview (SOFBI/ECFOS)

This is a multi-domain semi-structured interview which, apart from the domains later described, incorporates two self-reported scales on emotional concern (module 'E') and on the global impact of caregiving (module 'G'). The interview was originally developed for assessing family burden in persons with severe mental illness who live in the community in Spain (Martínez *et al.* 2000). It was developed and expanded from the *Family Burden Interview Schedule – Short Form* (Tessler & Gamache 1996), due to problems observed in our cultural environment on the feasibility and content validity of the original instrument. The framework and the domains included in the interview were revised (Salvador-Carulla & Martínez 2001), and modifications on the original instrument were discussed in series of five-expert focus groups by the PSICOST interest group on family burden. At last, usability of the instrument was piloted in both family burden and costs of illness studies in Spain (Agustench *et al.* 2000; Martínez *et al.* 2000). The SOFBI (or ECFOS in its Spanish acronym) has an introductory section plus eight modules which assess different domains of family burden. Each of these modules is assessed via yes/no questions or Likert-combined numerical and verbal scales. The introductory section includes 11 questions related to completion and caregiver characteristics. Module 'A' (ADLs) records assistance with the activities of daily life, the subjective burden (worries and distress) related to this assistance and the objective burden (frequency and time of care provided to ADLs). Module 'B' (behaviour) records supervision of behavioural problems and related burden, again both subjective and objective. Module 'C' (costs) gathers information on out-of-pocket costs related to care and daily living. Module 'D' (dedication) provides information on the dedication to care and replacement of the primary caregiver by other carers. Module 'E' (emotional concern) rates the worry about the daily routines (including worries about future) of the PWID by the primary caregiver using a self-reported seven-item scale. Module 'F' (functioning) explores the impact of care on the functioning of the primary caregiver life domains (work, social relationships and leisure), while module 'G' (global impact) provides information on the impact of caregiving both in the principal caregiver and in the family as a whole. Positive and negative impacts are measured separately, as they can be present at the same time. Module 'H' (health) provides information on the impact on the caregiver's health: health status, use of health services and days lost at work related to these health problems.

In the original schizophrenia sample, Cronbach's alpha coefficients were 0.85 for the overall interview, and the kappa coefficients for the test–retest validation were between 0.61 and 1.0. Factorial analysis found four principal components: assistance in daily activities, supervision of behavioural problems, and impact on caregiver's functioning plus emotional concern about the relative with severe mental illness (Martínez *et al.* 2000).

World Health Organization Disability Assessment Schedule – 2nd Version (WHO DAS-II)

The first version of this instrument developed by the WHO was designed for assessing the problems involved in the behaviour and social adjustment of persons with mental illness, as well as for identifying the factors that could influence these problems. Recently, and after modifying and clarifying the conceptualization of *disability*, the WHO (2000) has developed a new version of the instrument (WHO DAS-II), which encompasses impact on the functioning of those not only with mental illness, but with any other (physical as well as mental) type of health condition. It stands apart from other instruments for measuring the state of health, disability or functioning, in that it has been developed interculturally and tested in 16 languages in 14 countries. Moreover, it is conceptually compatible with the *International Classification of Functioning, Disability and Health*, known as the (ICF). In the present study, the interviewer 36-item version (proxy) was

used, as well as the algorithms developed by the WHO for computing the final scores.

Procedure

Two psychologists with rich experience in care for PWID were trained and standardized in the use of the SOFBI/ECFOS. After obtaining informed consent, a rater collected sociodemographic data on the family members and the users via a short interview designed to this purpose. Then the SOFBI/ECFOS and the WHO DAS-II were administered to the identified primary caregiver. In 30 randomly selected cases, another rating was provided by a second evaluator blind to the first assessment. Another 30 randomly selected cases were interviewed again 1 week later to obtain test–retest data. At the end of this procedure, a feasibility questionnaire was administered, including questions on time completion, item relevance, content comprehensiveness, overall understanding and acceptability of the questions, quality of the instrument's information and instructions, and interviewee fatigue. The final psychometric description was analysed by members of the PSICOST interest group on family burden, and final applications were drawn.

Statistical analysis

The psychometric properties of the SOFBI were analysed following standard guidelines (Salvador-Carulla & Salas 2001). Internal consistency was calculated using Cronbach's alpha coefficient. Two different types of statistical tests were used to calculate test–retest and inter-rater reliability. The kappa index was used in categorical items, whereas weighted kappa index was used for ordinal items. Kappa values were transformed into ordinal measures (kappa: poor <0; low 0–0.2; fair 0.21–0.4; moderate 0.41–0.6; strong 0.61–0.8; and nearly perfect 0.81–1) (Kramer & Feinstein 1981). Kappa was not calculated on items with a low prevalence of answers and low variability (Spitznagel & Helzer 1985). Construct validity was analysed with a maximum-likelihood factor analysis. Convergent validity was tested by applying Pearson's correlation between the totals of the SOFBI/ECFOS and WHO DAS-II scales. SOFBI/ECFOS feasibility was judged adequate when 70% of the responses were on the two upper points of the Likert scale ('quite' or 'a great deal') (Martínez *et al.* 2000).

The statistical packages used were the Statistical Package for Social Sciences, version 12.0 (SPSS Inc. 2004) and Stata Statistical Software, version 8.0 (Stata Corp. 2003).

Results

Internal consistency

Table 1 shows the Cronbach's alpha coefficients for the global interview as well as for the subdomains of the SOFBI. The modules 'C' (costs), 'D' (dedication by others) and 'H' (health) did not include quantitative ratings and were therefore not included in this analysis. SOFBI/ECFOS items show a high homogeneity in the four dimensions assessed with alpha values ranging from 0.69 to 0.85, with a global internal consistency of 0.88.

Reliability

Test–retest reliability values are summarized in Table 2. Items in module 'A' (assistance with ADLs), module 'C' (out-of-pocket costs) and module 'H' (impact on caregiver's health) showed moderate to strong agreement. In module 'B'

Table 1 Psychometric properties of the Subjective and Objective Family Burden Interview (SOFBI/ECFOS). Internal consistency of scores at modules with quantitative ratings ($n = 166$)

Internal consistency SOFBI/ECFOS	Cronbach's alpha
ECFOS-II (intellectual disability)	0.88*
Module 'A': assistance with activities of daily life	0.79†
Module 'B': supervision of behavioural problems	0.69†
Module 'E': emotional concern about the relative with ID	0.82
Module 'F': caregiver's functioning	0.75
Module 'G': global impact (negative)	0.74

* 0.87 when the items suggested by the factor analysis were eliminated.

† Did not vary when the items suggested by the factor analysis were eliminated.

ID, intellectual disability.

Table 2 Psychometric properties of the Subjective and Objective Family Burden Interview (SOFBI/ECFOS): Test–retest reliability (Cohen's kappa coefficient) ($n = 30$)

SOFBI/ECFOS	Cohen's kappa
Module 'A': activities assistance with activities of daily living	
Self-care	0.667
Medication	0.471
Housework	0.529
Shopping	0.630
Family routine	0.783
Transportation	0.535
Personal finances	0.585
Organizing time	0.634
Attending appointments	0.492
Administrative affairs	0.630
Module 'B' behaviour: containment of behavioural problems	
Disruptive behaviours	0.429
Demand for attention	0.348
Disruptive behaviours at night	*
Aggression towards others	0.516
Aggression towards self	0.630
Alcohol abuse	*
Drug abuse	*
Module 'C' costs: out-of-pocket expenses	0.648
Module 'D': dedication and replacement by other carers	0.550
Module 'E': emotional concern about the relative with ID	
Physical safety	0.245
Treatment	0.048
Social life	0.481
Physical health	0.263
Everyday life	0.343
Money	0.403
Relative's future perspectives	0.450
Module 'F': impact on caregiver's life module	
Work	*
Social life	0.559
Housework	0.550
Attention given to other family members	0.789
Module 'H': impact on caregiver's health module	0.783

* Reliability not calculated, as one of the variables studied was a constant.

(supervision of behavioural problems), the level of agreement was moderate for the majority of the items, except for the item 'demand for attention', where agreement was only fair. The agreement was fair to moderate in module 'E' (emotional concern about the relative with ID).

The inter-rater agreement coefficients are shown in Table 3. The agreement was nearly perfect in four modules (A, C, D and H), whereas modules 'B' and 'F' showed a strong to nearly perfect agreement, although several items could not be tested in these two domains due to lack of variability.

Validity

SOFBI/ECFOS construct and convergent validity were analysed. Content and face validity partially overlap with feasibility and were explored in this other analysis.

Construct validity was explored through two-factor analyses. First, an exploratory maximum-likelihood factor analysis was carried out, and 10 factors with eigenvalues >1 were found, which explained 68% of the scale's variance. After eliminating three items (medication intake, care appoint-

Table 3 Psychometric properties of the Subjective and Objective Family Burden Interview (SOFBI/ECFOS): Inter-rater reliability (Cohen's kappa coefficient) ($n = 30$)

SOFIB/ECFOS	Cohen's kappa
Module 'A': assistance with activities of daily living	
Self-care	1.00
Taking medication	1.00
Housework	1.00
Shopping	1.00
Family routine	1.00
Transportation	1.00
Personal finances	1.00
Organizing time	*
Attending care appointments	0.923
Administrative affairs	1.00
Module 'B': behavioural problems' supervision	
Disruptive behaviours	1.00
Demand for attention	0.870
Disruptive behaviours at night	*
Aggression towards others	0.783
Aggression towards self	1.00
Alcohol abuse	*
Drug abuse	*
Module 'C': costs (out-of-pocket expenses)	1.00
Module 'D': dedication and replacement by other carers	1.00
Module 'E': emotional concern about the relative with ID	
Physical safety	0.927
Treatment	0.841
Social life	0.927
Physical health	1.00
Everyday life	0.962
Money	1.00
Relative's future perspectives	0.93
Module 'F' functioning: impact on caregiver's functioning	
Work	*
Social life	*
Housekeeping	1.00
Care given to other family members	1.00
Module 'H' health: impact on caregiver's health	1.00

* Reliability not calculated, as one of the variables studied was a constant.

ments and suicide surveillance), and those modules with a single quantitative item that represented a factor in themselves ('C' costs, 'D' dedication by others, and 'H' impact on the caregiver's health), a second maximum-likelihood factor analysis was carried out, this time confirmatory with four factors (Bartlett's sphericity test: $\chi^2 = 1722$; degrees of freedom = 406; $P < 0.01$). These factors, which explained 40% of the scale's variance, show a simple structure, with each item adequately saturating a single factor. The instrument's structure of the following three domains was supported by the factorial analysis: 'A' (assistance with everyday activities), 'B' (behavioural problems), 'E' (emotional concerns) and 'F' (impact on the caregiver's functioning) (Table 4).

The WHO DAS-II was used to explore convergent validity. The a *priori* hypothesis was that family burden was related to the functioning of the relative with ID. Therefore, a Pearson's correlation study was carried out between the scores on the SOFBI/ECFOS and the WHO DAS-II. A correlation of 0.67 was found between both scales.

Table 4 Psychometric properties of the Subjective and Objective Family Burden Interview (SOFBI/ECFOS): Construct validity ($n = 166$). Saturation of the items on the 4 proposed factors

	Factor I	Factor II	Factor III	Factor IV
	% of variance			
Content of the item	**9%**	**16%**	**6%**	**5%**
Assistance with activities of daily living				
Self-care (objective burden)		0.358		
Self-care (objective burden)		0.284		
Housework (objective burden)		0.341		
Housework (objective burden)		0.482		
Shopping (objective burden)		0.383		
Shopping (objective burden)		0.439		
Transportation (objective burden)		0.291		
Transportation (objective burden)		0.496		
Personal finances (objective burden)		0.345		
Personal finances (objective burden)		0.487		
Containment of behavioural problems				
Disruptive behaviours (objective burden)	0.290			
Disruptive behaviours (objective burden)	0.316			
Demand for attention (objective burden)	0.630			
Demand for attention (objective burden)	0.999			
Aggression towards others (objective burden)	0.217			
Aggression towards others (objective burden)	0.247			
Impact on the caregiver's functioning				
Work				–0.204
Social life				–0.458
Housework				–0.462
Attention given to other family members				–0.496
Emotional concerns				
Physical safety			0.455	
Treatment			0.539	
Social life			0.539	
Physical health			0.404	
Everyday life			0.599	
Money			0.484	
Relative's future perspectives			0.401	

Maximum-likelihood factor analysis.

Feasibility and applicability

The SOFBI/ECFOS was judged positively by the staff. Its domains and questions were necessary, sufficient, appropriate to collect the target information, and easily understood and accepted by interviewees (Table 5). The SOFBI is a user-friendly interview which can be completed in 0.5 h. A review by the PSICOST focus group of the psychometric report recommended the use of separate modules when a full assessment of family burden in not required in the study: modules 'A' and 'B' were defined as the core modules of the SOFBI in agreement with the selected framework and with the data on reliability and validity.

Discussion

The present study describes the psychometric properties of an interview for assessing family burden in primary caregivers to adults with ID (SOFBI). Several limitations should be noted. The sample was limited to a single vocational centre, and it did not

Table 5 Psychometric properties of the Subjective and Objective Family Burden Interview (SOFBI/ECFOS): descriptive feasibility

SOFBI/ECFOS feasibility questionnaire	***n* (%)**
Are the questions on the instrument necessary?	
Not at all	0 (0)
A little	4 (8.2)
Quite a bit	38 (78)
A great deal	7 (13.8)
Are the questions on the instrument sufficient?	
Not at all	0 (0)
A little	3 (6.1)
Quite a bit	32 (65.3)
A great deal	14 (28.6)
Does the instrument adequately collect information?	
Not at all	0 (0)
A little	5 (10.2)
Quite a bit	39 (79.6)
A great deal	5 (10.2)
Does the interviewee understand the questions well?	
Not at all	0 (0)
A little	9 (18.4)
Quite a bit	29 (59.2)
A great deal	11 (22.4)
Does the interviewee accept the questions well?	
Not at all	0 (0)
A little	2 (4.1)
Quite a bit	32 (65.3)
A great deal	15 (30.6)
Did the interviewee become fatigued during the interview?	
Not at all	0 (0)
A little	14 (28.6)
Quite a bit	31 (63.3)
A great deal	4 (8.1)

include caregivers to persons with profound or severe ID. The two raters were part of the staff of the centre and therefore had a detailed knowledge of the PWID participating in this study. Moreover, the subsample of the reliability testing was small, and the low variability found in response to several items impeded the analysis of the full instrument, particularly in modules 'B' and 'F'. Although the instrument is based on another interview used previously in severe mental disorders in English-speaking countries (Tessler & Gamache 1996), the psychometric analysis has been carried out in Spain, and results cannot be generalized unless it is translated and tested in other countries.

Although the analysis of the psychometric properties of the SOFBI showed appropriate results with regard to its feasibility, consistency and reliability, the high inter-rater agreement obtained in this study cannot be generalized to routine clinical practice in other community settings, as the interviewers had previous and detailed knowledge of the users involved in this study. As expected, the test–retest agreement was lower than the inter-rater agreement. However, agreement coefficients were appropriate except for four items. The lower, though acceptable, coefficient of the item regarding treatment at the 'E' module (emotional concern) may be related to a different understanding of what 'treatment' means in this population group in comparison with the original sample of persons with severe mental illness. The factor analysis indicates a good construct validity, which fits the original modules of the instrument. Again, items related to treatment (medication intake, attending care appointments) and supervision of suicidal behaviour seemed to behave in a different way than the rest of the items

which conformed the scale, which may suggest that these items should be disregarded in a future use of the SOFBI in PWID, with no implications to the internal consistency of the scale (as could be seen in Table 1). As a matter of fact, the surveillance of these behaviours is probably not core to burden in PWID while it probably is in severe mental illness. Convergent validity with the WHO DAS-II provided an additional value to the SOFBI, given the relationship between the measurements of functioning (WHO DAS-II) and burden (50% of the variance of scale is explained by functioning). The modular structure of the SOFBI allows a use of separate modules of the instrument when a full and comprehensive assessment of family burden is not required. The interest group defined two core modules of the instrument ('A' and 'B') based on reliability and validity results.

The SOFBI is a valid and reliable instrument for assessing the family burden experienced by principal caregivers to adults with ID in a vocational setting. In contrast with the adult population, a series of instruments have been validated in primary caregivers to children and adolescents with ID, such as the Nijmegen Family Situation Questionnaire (Wels & Robbroeckx 1996), or the Impact on Family Scale (IFS/FaBel) (Ravens-Sieberer *et al.* 2001; Thyen *et al.* 2003). Although the IFS/FaBel does not provide information on positive aspects of care nor is validated in the adult population, it is a good example of the approach followed here. IFS was developed in the Anglo-American literature as a self-report instrument to assess the consequences of chronic conditions and disability in childhood and adolescence for the family. It provides information on the financial impact of care. The IFS/FaBel was translated and validated into the German language, including construct validity, good internal consistency and discriminant validity (Ravens-Sieberer *et al.* 2001). The IFS/FaBel has been used thereafter to determine the independent effect of unmet health needs on family burden, in addition to the effects of functional impairment and parental care load, in children and adolescents with disabilities including ID (Thyen *et al.* 2003).

The SOFBI, IFS/FaBel and other related instruments facilitate the assessment and detection of the impact of caring on the families with a relative with ID. These instruments may contribute to the assessment and monitoring of financing incentives, clinical interventions and services targeted to this key population group.

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7.3. Family impact in individuals with intellectual disability, mental health disorders and dual diagnosis. A comparison.

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Title:

Family impact in intellectual disability, severe mental health disorders and mental health disorders in ID. A comparison.

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1. Introduction

The term ‘family burden’ has been introduced to describe the adverse consequences of taking care of *severely disturbed psychiatric patients* (Treudley, 1946). More recently, the term ‘impact’ has been proposed as an alternative to ‘burden’, assuming that taking care of a relative with disability has not only adverse costs for the family, but also positive consequences (Blacher & Hatton, 2001; Hastings, Beck, & Hill, 2005; Blacher, Baker, & MacLean, 2007).

Although initial studies tended to focus on the figure of the main caregiver, it has broadened to also include burden associated to the rest of the family members (Schene, Tessler, & Gamache, 1966). Family burden is usually divided into objective and subjective burden (Hoening & Hamilton, 1966), being objective burden related to observable and concrete demands, while subjective burden is related to the emotional costs and the extent to which family members perceive they are carrying a burden.

When considering people experiencing severe mental disorders like schizophrenia, it is long acknowledged that the raise of psychiatric community services has increased burden on families (Mandelbrote & Folkard, 1961). Less attention has been paid to the case of people with ID to date (Wodehouse & McGill, 2009). However, the progressive recognition of their rights and values, the process of de-institutionalization undergone in the last few decades and recent changes in family structures have contributed to the growing interest in the situation of families taking care of a member with ID. Likewise, the acceptance of the biopsychosocial model as a framework for understanding disability (World Health Organization [WHO], 2001) has highlighted the importance of the family’s role due to the links between biological, psychological and social dimensions that such a model introduces. Thus, family burden (or family impact) is a concept born in the field of psychiatric disorders that has been successfully exported to the ambit of ID.

Nevertheless, such a multidomain, complex and global concept should be understood more deeply and differences in the burdening genesis should be

addressed in order to better analyse the concept and therefore design more effective interventions. Apart from impacting families' mental health and quality of life (Floyd & Gallagher, 1997; Gallagher, Phillips, Oliver, & Carroll, 2008; Hastings, Daley, Burns, & Beck, 2006; Aznar & Castañón, 2005; Hassall, Rose, & McDonald, 2005; Emerson, Robertson, & Wood, 2004), family burden has been acknowledged to influence the outcomes of the disability condition (Perlick, Stastny, Mattis, & Teresi, 1992; Falloon, 1985; Perlick, Rosenheck, Clarkin, Raue, & Sirey, 2001; Perlick et al., 2004), generating a circular relationship between quality of life in both individuals and their families.

However, very few comparative studies of diverse disabling conditions have been undertaken. It has been stated (Maes, Broekman, Došen, & Nauts, 2003) that caregiving to people with mental health disorders and intellectual disabilities has a higher impact on families than the sole condition of intellectual disabilities. The underlying hypothesis of challenging behaviours accounting for most of family burden has already been stated (Emerson et al., 2001). Moreover, autism has been found to cause more stress to caregivers compared to other diagnosis such as Down syndrome (Blacher & McIntyre, 2006). Regarding economical costs, children without disabilities and children with autism, physical disabilities and mental disabilities have been compared (Xiong et al., 2010), finding significant differences in raisings expenses.

Differences in burden associated to mental health disorders, burden associated to ID, or the interaction of both (MH-ID) should also be expected, highlighting which models of services should be designed to address the needs of families and therefore pursue a better communitarian framework of services.

2. Material and methods

2.1. Participants

Participants were recruited from three different settings throughout Spain. The ID group was gathered within workers of the Carmen Pardo-Valcarce

Foundation's sheltered employment programme and clients of sheltered workshops in the same Foundation. The Pardo-Valcarce Foundation provides community care services for over 450 persons with ID in Madrid (Spain), including educational and vocational services. The ID group consisted of 72 participants with a mean IQ of 58.92 (range: 36-73, SD=7.63) as measured by the Wechsler Adult Intelligence Scale-III (WAIS-III). Individuals from the ID group had a mean age of 28.61 years (range: 20-55 years, SD=5.84) and 59.7% were male. Participants with any prior or present psychiatric diagnosis or with behavioural problems were previously excluded from the group (internal reports measured by means of the PAS-ADD interview (Moss et al., 1993) and ICAP (Bruininks, Hill, Weatherman, & Woodcock, 1986; Montero, 1996). The schizophrenia group (n=203) data were provided by the scientific association PSICOST and were originally gathered from individuals with ICD-10 diagnosis of schizophrenia from four Community Mental Health Sites [Barcelona (Gavà Mental Health Care Site [MHCS]), Madrid (Salamanca MHCS), Granada (MHCS La Loja) and Navarra (MHCS Burlada)]. Participants had a mean age of 37.97 years (SD=8.29) and 71.6% were male. The group of mental health disorders in ID (MH-ID) was recruited from the Parc Sanitari Sant Joan de Déu Health Care Site in Sant Boi de Llobregat, Barcelona (Spain) and was defined as individuals meeting both criteria of IQ<70 and ICD-10 diagnosis of a comorbid psychiatric disorder (WAIS-III and PAS-ADD respectively). It consisted of 90 participants with a mean IQ of 53.53 (range: 45-73, SD=7.06). Participants had a mean age of 30.77 years (range: 17-54 years, SD=8.29) and 45.6% were male. As for ICD-10 disorders diagnosed: schizophrenia, schizotypal or delusional disorders (F20-F29), n=26 (28.9%); mood (affective) disorders (F30-F39), n=11 (12.2%); neurotic, stress-related or somatoform disorders (F40-F48), n=22 (24.4%); disorders of adult personality or behaviour (F60-F69), n=16 (17.8%); others; n=15 (17%). All participants were informed about the project and letters were sent to their relatives. Afterwards, they were asked for their informed consent.

2.2. Instrument

Burden experienced by caregivers was assessed with the ECFOS-II / SOFBI-II scale (*Entrevista de Carga Familiar Objetiva y Subjetiva* / *Objective and Subjective Family Burden Interview*). The SOFBI-II scale is a survey tool that has been elaborated by the PSICOST Group in order to assess family burden. The interview was initially aimed at principal caregivers to people with schizophrenia who lived in the community (Vilaplana et al., 2007); however, the scale has recently been validated for people with ID (Martorell, Pereda, Salvador-Carulla, Ochoa, & Ayuso-Mateos, 2007). Developed and expanded from the FBIS-SF *Family Burden Interview Schedule –Short Form*, the SOFBI has an introductory section plus 7 modules which evaluate different domains of family burden (a final optional descriptive module is also included):

1) The *introductory section* includes 11 questions related to completion and caregiver characteristics;

2) *Module A* records assistance with the activities of daily living, the subjective burden (worries and distress) related to this assistance and the objective burden (frequency and time of care provided);

3) *Module B* records supervision of behavioural problems and related burden, again both subjective and objective;

4) *Module C* gathers information on out-of-pocket expenses related to care and daily living;

5) *Module D* explores the impact of care on the functioning of the primary caregiver life domains (work, social relationships, leisure);

6) *Module E* rates subjective burden (such as worry about well-being, quality of life, future of the person with ID…) experienced by the primary caregiver, assessed using a self-reported 7-item scale.

7) *Module F* provides information on the dedication to care and replacement of the primary caregiver by other carers;

8) *Module G* provides information on the impact on the caregiver's health: health status, use of health services and days lost at work related to these health problems.

Each of these modules is quantified via yes / no questions or Likert combined numerical and verbal scales. A total score can be obtained in order to estimate the total level of burden.

2.3. Statistical analyses

Mean total scores and mean scores for each SOFBI module were computed using the Statistical Package for the Social Sciences (SPSS version 15). Relationship between age and gender and total and module scores were explored for each diagnostic group using t-tests and chi-square tests. One-way ANOVA (followed by post-hoc comparisons between pairs of groups) was performed to test the differences in total mean scores and modules scores for the three diagnostic groups.

3. Results

3.1. Within-group analyses

For both ID and MH-ID, we explored whether level of burden was related to age or gender (see table 1). Comparisons were not performed for the schizophrenia group due to unavailability of matched data.

Regarding gender, results of t-tests and chi-square showed no significant differences of burden between males and females neither in the ID group (module A: t=1.20, P=0.23; module B: t=0.66, P=0.51; module D: t=1.25, P=0.22; module E: t=1.30, P=0.20; module F: X^2=0.54, P=0.46; total: t=0.62, P=0.54) nor in the DD group (module A: t=-0.72, P=0.47; module B: t=0.70, P=0.49; module D: t=1.40, P=0.17; module E: t=0.18, P=0.86; module F: X^2=0.03, P=0.86; module G: X^2=0.51, P=0.47; total: t=0.97, P=0.34).

When considering age, two sub-groups were defined attending to their median (ID group: median=27; dual diagnosis group: median=30). Significant differences arose in module E in the ID group (P<0.05), showing less family burden in the eldest group, but not in the rest of the modules (module A: t=1.73, P=0.09; module B: t=1.36, P=0.18; module D: t=0.34, P=0.74; module E: t=2.14, P=0.04; module F: X^2=0.00, P=0.99; total: t=0.24, P=0.81). No significant differences were found for the MH-ID group (module A: t=1.54, P=0.13; module B: t=1.82, P=0.07; module D: t=1.55, P=0.12; module E:

t=1.75, P=0.08; module F: X^2=0.00, P=0.99; module G: X^2=0.40, P=0.53; total: t=1.44, P=0.15).

3.2. Between-group analyses

Results for One-way ANOVA showed significant differences in total score of family burden between diagnostic groups, $F_{2,362}$=81.80, P<0.001. Results of Games-Howell *post-hoc* tests for unequal variances showed that the MH-ID condition presented the highest degrees of family burden, followed by the schizophrenia group and being the ID condition the least burdening.

When taking specific modules into account, all of them were significantly higher for the MH-ID group. However, significant differences between schizophrenia and ID module scores were found in modules B and D (module B is expected, regarding challenging behaviours were excluded in the ID group), with no significant differences in modules A and E (see Table 2 for more details).

TABLE 2

Results for chi-square analysis showed significant differences in module F and G scores between diagnostic groups (P < 0.001, see Table 3 for more details). The MH-ID group had significantly less replacement by other carers and a significant higher impact on caregiver's health. The schizophrenia group, though significantly less than the MH-ID group, also aroused health problems on the carer whereas the ID group did not.

TABLE 3

4. Discussion

Results suggest that taking care of a sibling with MH-ID burdens families in a higher degree than taking care of someone with schizophrenia or ID. People not familiar with ID may tend to think that it is the ID condition the origin of family

burden, concluding therefore that the arising of a mental health problem would not impact carers that much.

As Reiss *et al.* stated when illustrating the diagnostic overshadowing effect (Reiss, Levitan, & Szyszko, 1982), intellectual disability overshadows the individual and extensively their families, applying the perceptional heuristic of seeing the effect of mental health disorders smaller than real because of being presented besides an already existing disability (Jopp & Keys, 2001). Our data suggest that when a mental health problem ensues, families are highly impacted, independently of a previous diagnosis of ID. Even more, we can conclude that the sole condition of ID, though generating family impact, is less significant that the one caused only by psychiatric symptoms, concluding that the interaction generates a higher impact than when presented separately.

As results highlight, families taking care of someone with ID are worried about the future of their relative (module E) and have to spend some of their time helping him or her with activities of daily living (module A). This should obviously be taken into account when designing supports and policies for caregivers to people with ID, but it should be considered that this situation is highly impacted by the apparition of psychiatric symptoms, something very common between people with ID (Campbell & Malone, 1991; Menolascino & Fleisher, 1991; Borthwick-Duffy, 1994; Cooper, Smiley, Morrison, Williamson, & Allan, 2007). For Spanish population see Salvador-Carulla, Rodriguez-Blazquez, Rodriguez, Perez-Marin, and Velazquez (2000).

Derived from the research on the care for elderly people, two main explaining theories have been proposed to understand the process of familiar adaptation and its evolution over the life span: the *wear and tear hypothesis* and the *adaptational hypothesis*. The first states that both physical and psychpological depletion should be expected for caregivers in the long term, as their –physical and psychological- resources get progressively exhausted (Johnson & Catalano, 1983). On the other hand, the later suggests that the familiar adjustment to the caregiver role improves over time (Townsend, Noelker, Deimling, & Bass, 1989), more in view with the actual resilience theories. Our

results tend to show that the arousal of psychiatric symptoms in a family system would better suit the *wear and tear* hypothesis, while ID carers would probably suit more the adaptational one. First, while ID is early diagnosed (commonly in childhood), the usual onset of mental illness in adolescence implies a later diagnosis. Second, the course of ID is more stable than the course of mental illness. Moreover, results from the within-groups analysis stress this assumption. For instance, significant differences found in module E when considering age in the ID group show that the higher level of burden is associated to the youngest group. Reduction of the caregiver's motives of concern as age increases could be understood as a result of an adaptation process. Concerns about the future are equally present in schizophrenia and ID (module E), and the amount of time and concerns aroused by activities of daily living (module A) as well as replacement by other carers (module F) are the same for both groups. But, aligned with the *wear and tear hypothesis*, taking care of someone with schizophrenia has a significantly higher impact on his or her life domains (module D) as well as on the carer's health (module G).

As time passes and distance increases from the de-institutionalization process, the role of the family in caring for individuals with disability will become even more pronounced as central to the biopsychosocial model of mental health care. Actual policies, as the recently approved Spanish Dependency Law, reflect the importance of caregivers as part of the care system of people with disability and therefore more research is needed in order to understand their needs and supports.

Finally, a limitation of this study should be noted. It should be pointed out that our participants only present mild-to-moderate ranges of intellectual disability; therefore, our conclusions are not generalizable to ID groups with more support needs.

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Table 1. Burden scores (mean and standard deviation) for diagnosis groups, gender, age and IQ.

	Module A	Module B	Module D	Module E	Module F	Module G	Total
ID group							
Gender							
Male (n=43)	1.18 (1.10)	0.17 (0.40)	0.84 (1.37)	5.85 (2.92)	2.79 (5.13)	0.00 (0.00)	1.66 (1.43)
Female (n=29)	1.55 (1.48)	0.24 (0.51)	1.31 (1.87)	6.78 (3.09)	3.72 (5.65)	0.00 (0.00)	1.86 (1.33)
Age							
<=27 (n=38)	1.57 (1.42)	0.27 (0.51)	1.09 (1.82)	6.92 (3.05)	3.16 (5.36)	0.00 (0.00)	1.78 (1.20)
>27 (n=34)	1.06 (1.04)	0.13 (0.35)	0.96 (1.32)	5.45 (2.79)	3.18 (5.37)	0.00 (0.00)	1.70 (1.57)
MH-ID group							
Gender							
Male (n=41)	3.70 (2.37)	2.67 (1.83)	4.73 (2.58)	10.16 (1.93)	6.15 (6.07)	3.22 (5.38)	5.22 (1.93)
Female (n=49)	3.38 (1.90)	2.97 (2.17)	5.50 (2.59)	10.24 (2.28)	6.37 (6.05)	2.45 (4.89)	5.60 (1.76)
Age							
<=30 (n=46)	3.20 (1.89)	3.21 (2.04)	5.56 (2.54)	10.58 (1.79)	6.26 (6.06)	3.13 (5.33)	5.70 (1.91)
>30 (n=44)	3.88 (2.30)	2.44 (1.94)	4.72 (2.62)	9.81 (2.37)	6.27 (6.06)	2.45 (4.90)	5.1 5 (1.74)

ID, Intellectual disability group; MH-ID, mental health in intellectual disability group.

Table 2. Impact differences between groups (modules A, B, D and E). Mean scores, standard deviations and results of ANOVA and *post-hoc* tests.

SOFBI Module	Diagnosis Group	Mean	SD	$F_{2,362}$	*Post-hoc*[#] (Games-Howell)
Module A: Activities of daily life	ID	1.33	1.27	44.39***	MH-ID>ID, Schz
	Schz	1.63	1.70		
	MH-ID	3.53	2.12		
Module B: Behavioral problems	ID	0.20	0.44	53.11***	MH-ID>ID MH-ID>Schz Schz>ID
	Schz	1.27	1.75		
	MH-ID	2.83	2.02		
Module D: Life Domains	ID	1.03	1.60	71.91***	MH-ID>ID MH-ID>Schz Schz>ID
	Schz	2.03	2.54		
	MH-ID	5.15	2.60		
Module E: Worries	ID	6.23	3.00	55.22***	MH-ID>ID, Schz
	Schz	6.60	3.17		
	MH-ID	10.20	2.12		
Total	ID	1.74	1.38	81.80***	MH-ID>ID MH-ID>Schz Schz>ID
	Schz	3.28	2.01		
	MH-ID	5.43	1.84		

ID, Intellectual disability group; Schz, Schizophrenia group; MH-ID, mental health in intellectual disability group.

[#] Only significant differences between groups are depicted (*P*'s<0.001).

*** *P*<0.001.

Table 3. Impact differences between groups (modules F and G). Percentages and chi-square test.

SOFBI Module	ID	Schz	MH-ID	X^2
Module F	YES: 73.6%	YES: 72.9%	YES: 47.8%	19.62***
Help from other carers	NO: 26.4%	NO: 27.1%	NO: 52.2%	
Module G	YES: 0%	YES: 10.8%	YES: 23.3%	21.35***
Health problems	NO: 100%	NO: 89.2%	NO: 76.7%	

ID, Intellectual disability group; Schz, Schizophrenia group; MH-ID, mental health in intellectual disability group.

*** $P<0.001$.

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8. Agrandando el sistema. El empleo.

8. Agrandando el sistema. El empleo.

Como apuntábamos al comienzo, desde una perspectiva biopsicosocial, los tentáculos de la relaciones que la enfermedad mental establece con el entorno y el entorno con ésta, abarcan todo el espectro de la vida del individuo.

Por eso, fuimos agrandando el marco de estudio, desde factores personales tales como los eventos traumáticos, al sistema familiar, para finalizar con implicaciones sociales.

El acceso trabajo es uno de los hitos sociales de nuestra cultura. Sin embargo, las personas con discapacidad intelectual tienen gravemente restringida su participación al empleo. El mayor marco de referencia para conocer la situación de empleo entre las personas con discapacidad en nuestro país sigue siendo la encuesta EDDES (IMSERSO; 1999). Es un estudio modelo, que ha sido ejemplo y reseña para otros países, pero que tiene la pequeña pega de que data de 1999. Aunque tras diez años esperamos que la situación haya variado ostensiblemente, los datos de la EDDES siguen arrojando proporciones que probablemente sigan siendo representativas a día de hoy.

Los datos recogidos en la Encuesta sobre Discapacidades, Deficiencias y Estado de Salud realizada en 1999 por el INE, reflejaban que en España había 1.337.708 personas con discapacidad en edad de trabajar (16 a 64 años). De ellas sólo el 32,1 % estaba en situación de actividad (la tasa de actividad en la población general es de 65,4 %). Recordemos que la tasa de actividad se refiere a la proporción de población en edad de trabajar que tiene un empleo o lo busca . Así, esta tasa de actividad quiere decir que dos de cada tres españoles con discapacidad en edad de trabajar ni se plantean buscar un empleo.

El segundo dato es el de una tasa de desempleo de 25,8 % (en la población general era entonces de un 16,6 %). Es decir, de aquellos que están dispuestos a trabajar, tres de cada cuatro consiguen un empleo.

Pero si analizamos estos datos atendiendo al tipo de discapacidad, observamos que aquellas personas que presentan una *deficiencia mental* como origen de su discapacidad tienen la tasa de actividad más baja de todas, 15.4 %, y la tasa de desempleo más alta, 44.6 %. O dicho de otra manera: sólo un 15.4% de las personas en edad de trabajar con discapacidad intelectual, del desarrollo o enfermedad mental, se plantean buscar un empleo. Y de esa pequeña minoría dispuesta a trabajar, sólo la mitad lo consigue.

8. Agrandando el sistema. El empleo.

	Números absolutos					Tasas	
	Total	Activos			Inactivos	Actividad	Paro
		Total	Trabajan	Paro			
Deficiencias mentales	257.465	39.666	21.855	17.8112	17.799	15,4%	44,9%
Deficiencias visuales	253.188	107.660	84.002	23.658	145.528	42,5%	22,0%
Deficiencias del oído	268.415	122.675	98.916	23.760	145.740	45,7%	19,4%
Deficiencias del lenguaje, habla y voz	16.060	4.542	3.656	886	11.5182	8,3%	19,5%
Deficiencias osteoarti-culares	490.446	147.011	102.834	44.177	343.435	30,0%	30,1%
Deficiencias del sistema nervioso	123.395	19.958	13.049	6.907	103.437	16,2%	34,6%
Deficiencias viscerales	115.065	19.000	13.290	5.711	96.065	16,5%	30,1%
Otras deficiencias	44.433	10.595	8.884	1.710	33.838	23,8%	16,1%
No consta	27.887	9.519	6.341	3.177	18.368	34,1%	33,4%
Total personas con discapacidad	1.337.708	431.841	319.185	112.657	905.867	32,3%	26,1%

2 Tasa de actividad = (población activa mayor de 16 años / población total mayor de 16 años) x 100
3 Tasa de desempleo = (número de desempleados / población activa) x 100

8. Agrandando el sistema. El empleo.

Entendiendo que son infinitos los factores que interactúan cuando la lupa se separa tanto como para entrar a analizar factores sociales de la magnitud del acceso al empleo, como último objetivo nos propusimos analizar la influencia de la discapacidad intelectual y de la presencia de problemas de salud mental en el acceso al empleo.

Como puede verse en el artículo *Identification of personal factors that determine work outcome for adults with intellectual disability* –finalista a los premios Caja Madrid de Investigación Social-2008-, estudiamos el efecto de la presencia de enfermedades mentales y alteraciones de conducta en el acceso al empleo, comparando un grupo de personas integradas en un recurso asistencial no laboral con un grupo de personas con discapacidad intelectual trabajadores de un centro especial de empleo. Pese a no poder establecer una direccionalidad por la no longitudinalidad del diseño experimental, sí encontramos que las enfermedades mentales y las alteraciones de conducta estaban significativamente más presentes en el grupo no laboral. Sorprendentemente, y como desarrollamos en el artículo, el CI no resultó explicar significativamente el modelo. Pese a lo esperado (el CI fue incluido para controlar su efecto, dando por hecho que lo habría), la "inteligencia" no era un factor que determinara el acceso al mercado laboral. Sí lo eran variables directamente relacionadas con presentar discapacidad intelectual, pero no las propias barreras cognitivas. Este hallazgo no hace más que ilustrar de nuevo el modelo que hemos expuesto a lo largo de este trabajo: la tremenda pluralidad de factores que interactúan en el fenómeno de la discapacidad intelectual.

8.1. Identification of personal factors that determine work outcome for adults with intellectual disability.

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Identification of personal factors that determine work outcome for adults with intellectual disability

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Abstract

Background Access to employment for people with intellectual disability (ID) has become a social priority. The aim of the present study is to try to determine which variables [sociodemographic variables, intelligence quotient (IQ), presence or absence of a psychiatric disorder, functioning, self-determination, and behavioural problems] could most reliably account for access to remunerated employment of people with ID.
Methods Two groups of people with ID participated in this study: (1) 69 workers in a sheltered-employment programme; and (2) 110 clients of programmes in sheltered workshops. Both programmes were run by the Pardo-Valcarce Foundation in Madrid (Spain). The following variables were assessed for every participant: IQ, functioning, behavioural problems, self-determination and presence of psychiatric symptoms. A binary logistic regression analysis was carried out in order to identify the variables that best explained work outcome (sheltered workshop programme vs. sheltered employment programme).
Results Although IQ showed no significant differences between the two groups of participants, the remaining variables did: behavioural problems, functioning, psychiatric symptoms and self-determination significantly explained work outcome. As for sociodemographic variables, whereas gender did not show any significant relationship with the labour status of the participants, significant differences were found when considering variables such as age and pension benefits.
Conclusions All the main variables considered, except IQ, turned out to be significant. Our findings should be considered encouraging, as they apparently show that both personal and social efforts can help individuals to overcome their low intellectual functioning in order to achieve access to employment. Such study highlights the importance of a prior psychopathological evaluation and efforts to enhance self-determination in order to improve work inclusion for people with ID.

Keywords behavioural problems, employment, intellectual disability, intelligence quotient, mental disorders, self-determination

Introduction

With the progressive recognition of the rights and value of people with intellectual disability (PWID), access to employment for this group has become a priority for societies and institutions. Sheltered

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employment programmes have proven to be a useful strategy to assist individuals who find barriers to working in a competitive employment setting in their local community. Although these programmes have provided a great number of PWID an opportunity to access employment, they should be considered a transitory measure rather than a definitive solution. Over decades of long debate about the appropriateness of segregated employment settings for PWID, a number of criticisms have been raised questioning the effectiveness of these strategies. The most common criticisms highlight the lack of independence of sheltered workers, who frequently depend on public programmes (Bellamy *et al.* 1986); isolation and segregation from the rest of the community (Wehman 1981); and difficulties in progressing into competitive employment (Murphy & Rogan 1995).

Although studies show a considerably lower employment rate compared with the general population (Taanila *et al.* 2005), sometimes providing a pessimistic picture of the issue (Richardson *et al.* 1988), most PWID are cost-efficient workers (Cimera 1998), show positive attitudes towards employment (Parmenter & Knox 1991; Li 2004), and even tend to view retirement with concern (Ashman *et al.* 1995). Advantages that employment can provide to PWID go beyond economic autonomy and include facilitation of a social support framework (Knox & Parmenter 1993) or a high level of perceived quality of life (QOL) (Kober & Eggleton 2005). Intelligence quotient (IQ) has been traditionally proposed as one of the main predictors not only of occupational outcome (Ward *et al.* 1981; Cimera 1998; McDermott *et al.* 1999; Beadle-Brown *et al.* 2005) but also of functional outcome (Beadle-Brown *et al.* 2005). Emotional adjustment (Ward *et al.* 1981), previous employment record (Ward *et al.* 1981; Reiter & Palnizky 1996), motivation (Rose *et al.* 2005), physical condition, gender, and age (McDermott *et al.* 1999) have also been proposed as relevant factors that may determine successful employment adjustment. Psychopathological variables should not be forgotten, as it is well known that the presence of challenging behaviours and psychiatric disorders seriously limits work outcome, being both significantly more present in PWID (Cooper *et al.* 2007).

In spite of the number of relevant studies that have been already published, more research remains to be done before conclusions can be reached regarding the factors that facilitate PWID's working outcome. Although most of the findings reported so far seem to be partially coincident, local differences should be expected, depending on the economic and employment polices implemented in each country. Therefore, it is necessary not only to pay attention to the development and evolution of national policies on the issue (Parmenter 1999), but also to remember that, in order to draw overall conclusions, it would be desirable to consider data from as wide a range of different countries as possible. Up to now, attention has been paid to the topic in Spain (Verdugo *et al.* 1998; Garcia-Villamisar & Hughes 2007); although more research on individual variables which could affect labour outcome in our country still remains to be done.

The Spanish Constitution of 1978 acknowledges the right of people with disabilities to equal access to opportunities in political, economical, cultural or social life. From the early 1980s, Spanish legislation has established, through the promulgation of such legislation as the 1982 Social Integration of Disabled People Act (known by its Spanish initials, LISMI), two different segregated employment settings for those PWID who find difficulties in integrating into the competitive labour force. Special Employment Centres (Centros Especiales de Empleo) are profitable businesses which provide a sheltered employment setting in which PWID are considered economically productive workers, with all the legal benefits derived from this role. For those people with higher levels of disability, Occupational Centres (Centros Ocupacionales) are sheltered workshop programmes intended to provide non-economically productive activities which can be regarded as occupational therapy and where the main goal is skill acquisition. And finally, although not included in the present study, supported employment in the community is now deservedly gaining ground among Spanish administrations and institutions, although better strategies and policies have yet to be implemented (Pallisera *et al.* 2003).

In spite of the above cited macrosocial variables, the main aim of the present study is to try to discriminate which personal variables for PWID in Spanish population (sociodemographic variables,

IQ, presence or absence of a psychiatric disorder, functioning, self-determination and behavioural problems) best explain access to remunerated employment. Similar studies have also monetary remuneration as a measure of work outcome (Reid & Bray 1997; Stephens *et al.* 2005).

Methods

A total of 179 adults with ID from the Carmen Pardo-Valcarce Foundation were interviewed, 69 of whom were working in the Foundation's sheltered employment programme at the time of the study, while the other 110 were clients of sheltered workshops in the same Foundation. The Pardo-Valcarce Foundation provides community care services for over 450 persons with ID in Madrid (Spain), including educational and vocational services, as well as specialised care for persons with psychiatric disorders and ID. Participants included 117 men (65.4%) and 62 women (34.6%), whose ages ranged from 20 to 65 years (mean age of 29.54 years, SD = 6.64). The degree of ID according to ICD-10 criteria and assessed through WAIS-III (Wechsler 2001), was mild (IQ 50–69) for 117 participants (65.4%), and 62 (34.6%) had moderate ID (IQ 35–49). No participants met severe-deep disability criteria.

All clients of the Foundation were informed about the project in groups of 20 participants, and letters were sent to their relatives. Afterwards, all clients of the Foundation were asked for their informed consent. Only one participant refused to give consent for the interview. An appointment was then made with carers of those participants who gave their consent. However, carers of 10 participants were unable to come for personal reasons, and seven participants were living on their own in a sheltered housing programme. Data were gathered administering a battery of different tests to the users/workers and their carers. Three psychologists with wide experience in ID assessed the participants.

Assuming type of employment as a dependent variable (sheltered workshop vs. sheltered employment programme), a number of variables were considered as possible independent ones:

• IQ. Spanish version of the Wechsler Adult Intelligence Scale – Third Edition (WAIS-III) (Wechsler 2001), which includes the traditional 11 tests from the previous version plus three new tests: matrices, symbol search and letter-number series.

• Functioning. The World Health Organization Disability Assessment Schedule – Second Version (WHO-DAS II) was originally published in 1988 by the World Health Organization (WHO) in order to provide a simple tool for evaluating disturbances in social adjustment and behaviour in people with mental disorders (World Health Organization 2000). The second version of the WHO-DAS scale considers the impact of any disorder on everyday functioning and is conceptually compatible with the WHO's new International Classification of Functioning, Disability and Health (World Health Organization 2001). Domains assessed by the WHO-DAS II include understanding and communicating, getting around, self care, getting along with others, household and work activities, and participation in society. The direct score used ranges from 36 to 180.

• Behavioural problems. The Inventory for Client and Agency Planning (ICAP) (Bruininks *et al.* 1986) is a tool designed for the assessment of adaptive and maladaptive behaviour, and gathers additional information to determine the type and amount of social assistance that people with disability may need. In our study, the Spanish version of the ICAP (Montero 1996) was used only for the purpose of evaluating behavioural problems, as functioning was already assessed by means of the WHO-DAS II. The general maladaptive index ranges from +5 to −70. High negative scores indicate severe behavioural problems.

• Self-determination. The Arc's Self-Determination Scale (ARC's) is a self-reporting scale that provides a measure of the construct 'self-determination' (Wehmeyer 1995). It has been designed for people with disability (particularly, intellectual and learning disabilities), and consists of 72 items grouped in four sections. Partial scores for each section evaluate the following features associated with the concept of self-determination: autonomy, self-regulation, empowerment and self-realisation. Altogether, these measures result in a global score of self-determination. A higher score implies a higher level of self-determination. The maximum score is 148 points. There is a Spanish version (Wehmeyer *et al.* 2006).

• Presence of psychiatric symptoms. The Spanish version of the Psychiatric Assessment Schedule for

Adults with Developmental Disability (PAS-ADD 10) (Gonzalez-Gordon *et al.* 2002) was used in order to evaluate the potential presence of psychiatric disorders (Moss *et al.* 1993, 1995, 1997). The PAS-ADD is a semi-structured interview for use with respondents who have ID, and for key informants. Based on items drawn from the SCAN (Schedules for Clinical Assessment in Neuropsychiatry), it includes features such as parallel interviewing of patient and informant, a three-tier structure to provide a flexible interview appropriate to the patient's intellectual level and simplified wording. However, in our study the CATEGO 5 algorithms were not used because they have shown lack of validity for the Spanish version (Gonzalez-Gordon *et al.* 2002) Therefore, after the interview, psychiatric diagnoses were made by an expert group designated for the study (composed of one expert psychiatrist and two expert psychologists).

In addition, the following sociodemographic variables were evaluated: gender, age, type of residence, and pension benefits.

The data obtained were analysed by means of the statistical computer program SPSS-13. After a descriptive analysis, comparative analyses (Student's *t*-test and chi-square) were performed in order to determine whether the relationship between work outcome and the considered variables was significant. Afterwards, the variables that showed a significant effect on work outcome were introduced in a binary logistic regression model in order to determine their significance for explaining the dependent variable.

Results

Results of chi-square and Student's *t*-tests comparing sociodemographic variables for both groups of participants (sheltered workshop vs. sheltered employment programme) are given in Table 1. Significant differences were found for age ($P < 0.01$) and pension benefits ($P < 0.001$).

Table 2 depicts the results of chi-square and Student's *t*-tests comparing intellectual and functional assessment, presence of behavioural problems, and psychiatric symptoms, as well as self-determination.

While the IQ showed no significant differences between the two groups of participants, the other global scores did: ICAP (behavioural problems) ($P < 0.02$), ARC'S ($P < 0.001$) and WHO-DAS II ($P < 0.001$). The presence of a psychiatric disorder was also significant ($P < 0.002$). With regard to different domains within each scale, significant differ-

Table 1 Differences in sociodemographic variables

	Frequency (%)			
Variable	**Sheltered workshop**	**Sheltered employment**	χ^2	***P<***
Gender				
Men	68 (37.99%)	49 (27.37%)	1.58	0.2
Women	42 (23.46%)	20 (11.17%)		
Type of residence				
Family home	103 (57.54%)	63 (35.20%)	0.367	0.8
Sheltered housing	6 (3.35%)	5 (2.79%)		
Independent housing	1 (0.56%)	1 (0.56%)		
Pension benefits				
None	34 (18.99%)	68 (37.99%)	79.16	0.001
Son/daughter in charge	73 (40.78%)	1 (0.56%)		
Orphan	1 (0.56%)	0 (0%)		
Orphan son/daughter in charge	2 (1.12%)	0 (0%)		
Variable	Mean (SD)		*t*	*P<*
	Sheltered workshop	Sheltered employment		
Age	28.57 (6.91)	31.09 (5.898)	−2.502	0.01

Table 2 Differences in clinical and functioning variables

Variable	Mean (SD)		t	*P*<
	Sheltered workshop	Sheltered employment		
IQ	61.86 (11.90)	62.83 (9.54)	−0.567	0.57
ICAP (behavioural problems, general index)	−5.88 (8.29)	−3.06 (7.04)	−2.22	0.02
ARC'S				
Autonomy	60.23 (13.45)	66.68 (9.91)	−3.42	0.001
Self-regulation	14.19 (2.63)	14.75 (1.89)	−1.54	0.1
Empowerment	14.12 (1.58)	14.57 (1.39)	−1.89	0.05
Self-realisation	12 (2.00)	12.55 (1.87)	−1.82	0.06
Total score	100.82 (16.38)	108.55 (12.06)	−3.35	0.001
WHO-DAS				
Understanding and communicating	12.05 (5.21)	8.64 (2.94)	5.18	0.001
Getting around	5.95 (2.89)	5.18 (0.575)	2.54	0.012
Self-care	6.59 (2.95)	4.68 (1.33)	5.50	0.001
Getting along with others	10.78 (4.93)	7.96 (4.26)	3.71	0.001
Household activities	8.03 (4.18)	5.41 (1.86)	5.34	0.001
Work activities	9.17 (5.16)	4.98 (2.37)	6.86	0.001
Participation in society	14.32 (6.05)	9.88 (2.45)	6.40	0.001
Total score	66.89 (22.76)	46.73 (10.82)	7.41	0.001
Variable	Frequency (%)		χ^2	*P*<
Psychiatric disorder:	Sheltered workshop	Sheltered employment		
Presence	52 (29.05%)	17 (9.50%)	9.17	0.002
Absence	58 (32.40%)	52 (29.05%)		

ICAP, Inventory for Client and Agency Planning; IQ, intelligence quotient; WHO-DAS, World Health Organization Disability Assessment Schedule.

ences were appreciated on all the subscales of the WHO-DAS II but only on two subscales of the ARC's: autonomy ($P < 0.001$) and empowerment ($P < 0.05$) (Table 2).

All the variables previously found significant were considered in a binary logistic regression analysis (method enter) in order to identify which of them better explained work outcome, with the exception of the WHO-DAS II score, as the effect of this variable seemed powerful enough to eclipse the contribution of the rest. Table 3 shows the results. The model showed a high percentage of correctly classified outcomes (69.6%), finding that the variables of presence/absence of a psychiatric disorder and self-determination were significant, while the variable behavioural problems were not.

Finally, two new analyses were performed with the aim of finding out which domains better explained work outcome on both the WHO-DAS II scale and ARC's scale. Results are shown in Tables 4 and 5. Subscales related to working skills and participation in society turned out to be the most significant functioning domains. As for self-determination, autonomy was the most significant area.

Discussion

Analysing the results for sociodemographic variables, a significant relationship was found between access to remunerated employment and the type of pension received ($P < 0.001$). The relationship between these two factors can be easily accounted for by Spanish legislation, which establishes that users of a sheltered employment programme must be legally regarded as wage-earning workers, thus making it impossible for them to receive any kind of publicly funded pension. Although this incompatibility is to be legally modified, it is currently in force. Moreover, mediation by other variables con-

Table 3 Predictors of remunerated emloyment: Binary logistic regression model and percentage of correctly classified outcomes

	Unstandardised coefficients					CI 95% for Exp (B)	
Variables	**B**	**ET**	**Wald**	**Sig.**	**Exp (B)**	**Lower**	**Upper**
Constant	–4.258	1.313	10.506	0.001	0.014		
ARC's total score	0.033	0.012	7.188	0.007	1.033	1.009	1.058
Presence of psychiatric disorder	0.818	0.385	4.519	0.034	2.265	1.066	4.813
Behavioural problems	0.019	0.026	0.545	NS*	1.019	0.969	1.072
Observed cases		Predicted cases				Percentage of success (%)	
		Sheltered workshop		Sheltered employment			
Sheltered-workshop		79		23		77.5	
Sheltered employment		29		40		58.0	
Overall percentage						69.6	

NS*, no significant for the model.

Table 4 Functioning variables as predictors of remunerated employment: binary logistic regression model and percentage of correctly classified outcomes

	Unstandardised coefficients					CI 95% for Exp (B)	
Variables	**B**	**ET**	**Wald**	**Sig.**	**Exp (B)**	**Lower**	**Upper**
Constant	4.717	1.354	12.138	0.000	111.789		
Understanding and communicating	–0.001	0.001	1.174	NS*	0.999	0.998	1.001
Getting around	0.002	0.002	0.460	NS	1.002	0.997	1.006
Self-care	–0.003	0.001	3.310	0.069	0.997	0.994	1.000
Getting along with others	0.001	0.001	1.417	NS	1.001	0.999	1.002
Household activities	0.000	0.001	0.214	NS	1.000	0.998	1.001
Work activities	–0.003	0.001	14.166	0.000	0.997	0.995	0.999
Participation in society	–0.002	0.001	7.211	0.007	0.998	0.996	0.999
Observed cases		Predicted cases				Percentage of success (%)	
		Sheltered workshop		Sheltered employment			
Sheltered-workshop		79		19		80.6	
Sheltered-employment		14		42		75.0	
Overall percentage						78.6	

NS*, no significant for the model.

sidered should be taken into account, e.g. being granted pension benefits is associated with a low level of functioning. With regard to age, significant differences were also predictable as, according to the regulations of the Carmen Pardo-Valcarce Foundation, only users who have previously participated in a sheltered workshop are allowed to move to a sheltered employment programme. Therefore, an older age is expected for those in the sheltered employment programme. Results regarding gender, however, seem more unexpected: no gender differences were found between both groups of participants. Although some literature extends gender differences in the general population to populations with ID (McDermott *et al.* 1999), our data seem to be consistent with results from other studies that

Table 5 Self-determination variables as predictors of remunerated employment: binary logistic regression model and percentage of correctly classified outcomes

	Unstandardised coefficients					CI 95% for Exp (B)	
Variables	**B**	**ET**	**Wald**	**Sig.**	**Exp (B)**	**Lower**	**Upper**
Constant	–4.033	1.916	4.432	0.035	0.018		
Autonomy	0.041	0.017	5.827	0.016	1.041	1.008	1.076
Self-regulation	0.016	0.080	0.040	NS*	1.016	0.869	1.118
Empowerment	–0.006	0.137	0.002	NS	0.994	0.760	1.300
Self-realisation	0.074	0.096	0.594	NS	1.077	0.892	1.300

Observed cases	Predicted cases		Percentage of success (%)
	Sheltered workshop	Sheltered employment	
Sheltered workshop	83	19	81.4
Sheltered employment	49	20	29.0
Overall percentage			60.2

NS*, no significant for the model.

suggest that PWID tend to be treated as gender-neutral persons rather than as men and women with gender preferences and needs (Umb-Carlsson & Sonnander 2006).

As for results related to clinical and functioning assessment, all the main variables considered turned out to be significant – except, somewhat surprisingly, IQ. This absence of a significant relationship between IQ and work outcome deserves further commentary. Traditionally, it has been assumed that one of the leading factors determining a person's employment is their IQ level. However, our findings seem to 'relativise' this widespread belief. Moreover, this should be considered encouraging, insofar as it apparently shows that both personal and social efforts can help individuals to overcome their low intellectual functioning in order to gain access to more competitive employment. This conclusion is in accord to our findings regarding functioning. Level of functioning is a significant variable that differentiates both groups considered. People working in the sheltered employment programme showed better results in all the areas of functioning assessed. The same could be said about the presence of behavioural problems: they are significantly more frequent in the group of users of sheltered workshops. The presence of behavioural problems will preclude a good functioning, hence causing a worse work outcome. This topic is particularly relevant, as it has been acknowledged that PWID tend to present more behavioural problems than people without disability (Stevens & Martin 1999; Emerson *et al.* 2001). In a similar vein, mental disorders are more frequent among PWID (Campbell & Malone 1991; Menolascino & Fleisher 1991; Borthwick-Duffy 1994; Cooper *et al.* 2007), although they are usually undiagnosed (Reiss & Szyszko 1982; Jopp & Keys 2001). This increase in the prevalence of mental disorders in PWID has also been observed in Spanish populations (Salvador-Carulla *et al.* 2000). All in all, results such as those highlight the importance of an appropriate previous psycopathological evaluation when considering employment for PWID. Instruments like the PAS-ADD, described above, could be taken into account in order to plan interventions orientated towards improving work outcomes for PWID.

Another significant variable, self-determination, is a term recently introduced in the ID field. It notes the degree to which a person with ID is able to lead his or her own life (Wehmeyer *et al.* 1996). This factor is especially relevant, as any action tending to improve a person's outcomes should be planned taking into account the person's desires and future plans. The importance of self-determination to enhance QOL for PWID has been empirically confirmed (Lachapelle *et al.* 2005). A number of studies have shown that objective outcomes are

more sensitive to capacity of choice than subjective indicators of QOL (e.g. personal satisfaction) (Perry & Felce 2003, 2005). Nevertheless, when analysing the relationship between self-determination and work outcome, a certain ambiguity related to circular causality is unavoidable. On the one hand, it seems evident that self-determination is a good predictor of positive work outcomes in lives of PWID (Wehmeyer & Schwartz 1997; Wehmeyer & Palmer 2003), insofar as we can expect that people who are self-determined are more likely to strive to achieve better employment opportunities (Wehmeyer & Bolding 1999). On the other hand, there is a general acknowledgement within the literature that competitive employment and community living settings enhance self-determination, offering the possibility of greater personal control and opportunities to make choices (Stancliffe *et al.* 2000; Stancliffe 2001; Wehmeyer & Bolding 2001). It has also been suggested that self-determination is further impacted by personal characteristics (Wehmeyer & Garner 2003). In conclusion, there are empirical reasons for considering self determination to be both a dependent variable and an independent variable. Within the framework of our study, we have assumed the second option (i.e. self-determination is a predictor of work outcome), but this assumption may constitute a limitation for our conclusions. Therefore, a longitudinal design would have been particularly advisable for our study, as it would have made it possible to carry out a follow-up on the variation of self-determination scores because of the shift from a sheltered workshop to a sheltered employment programme. However, a number of organisational difficulties precluded the possibility of implementing such a design. As our study assumes the framework of a cross-sectional design, causal nature of self-determination on work outcome can only be assumed, but by no means proven.

The main practical conclusion to be drawn is that PWID should take active part in decision making regarding their employment in order to achieve better opportunities. This conclusion seems to be consistent with results from other studies suggesting that self-determination should be promoted in all the stages of the search for employment in order to improve work outcomes for PWID (Timmons *et al.* 2001; Wehmeyer & Palmer 2003).

As it has already been noted, one variable (level of functioning assessed with the WHO-DAS) was excluded in the binary logistic regression model because it eclipsed the remaining variables. This multi-colinear problem can be accounted for by the high dependence established between functioning and some other variables (presence of psychiatric disorders or behavioural problems). The reason why behavioural problems were found non-significant in the analysis shown in Table 3 is probably a new multi-colinear effect: the presence of a mental disorder and the presence of behavioural problems are clearly interrelated (Hemmings *et al.* 2006).

Regression analyses undertaken showed, as noted above, that the WHO-DAS II domains of working skills and participation and the ARC's domain of autonomy were the most significant. Regarding functioning, these results point out that enhancing working skills and reducing possible barriers in the workplace are key factors when planning to improve work outcomes for PWID. As for self-determination, results highlight the importance of working with carers and families in order to support autonomy. It is well known that the presence of ID usually leads parents or other carers to provide excessive care. Among the consequences of this excess, we may find loss of opportunities for the person with ID. Carers might communicate their expectations of failure to PWID, so that when a particular problem arises in work environment (which is common in anyone's life), they are usually perceived as a confirmation of these negative expectations. Thus, negative expectations may turn into a barrier, leading PWID to move away from any competitive situation. Furthermore, it would be advisable for PWID to play the most active role of all the agents involved in the process of the employment search.

Finally, a few limitations of this study should be noted. First, as stated above, this is a cross-sectional study, which means that all data have been measured simultaneously and it is impossible to validly determine causes and consequences, which is a particularly relevant caveat when considering, for instance, the role of self-determination, as has been already noted. Second, it should also be pointed out that our participants only present mild-to-moderate ranges of ID; therefore, our conclusions are not generalisable to more severe ID groups. Also

regarding our participants, the closed nature of the study, carried out in a single setting, also restricts the generalisation of the data. Moreover, it must be indicated that a great number of variables may be involved in determining work outcomes for PWID, and we have only considered a few of them. In this sense, more attention should be paid to macro-variables that fall beyond the scope of our study, such as the role of the Administration, legislation in force and social prejudices. Finally, although remunerated employment seems a better labour situation for PWID (even more according to the levels established by the Spanish legislation before mentioned) employment in the community in non-segregated settings should be the goal for all labour inclusion policies.

Acknowledgements

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9. Traslación de los resultados. De la teoría a la práctica...

El recurso DIEM.

Como se desprende del capítulo 2, las personas con discapacidad intelectual son más vulnerables a desarrollar enfermedades mentales a lo largo de su ciclo vital. Sin embargo, éstas pasan desapercibidas, o son pobremente diagnosticadas y en cualquiera de los casos es muy difícil que reciban un tratamiento adecuado. En nuestro país, salvo en Cataluña, no existía ningún servicio para atender esta problemática. Esto nos llevó a diseñar el primer servicio en la Comunidad de Madrid para atender a aquellas personas que presentaran DI y alguna enfermedad mental o alteración de conducta, y que fue concertado por la Comunidad de Madrid en el año 2006. (Ver ANEXO I).

Asimismo, el conocimiento adquirido acerca de esta problemática nos llevó a la redacción de la guía para familiares y profesionales de Discapacidad Intelectual y Salud Mental (Ver ANEXO II), así como la participación en el estudio sobre el estado de la cuestión llevado a cabo por FEAPS:

Salvador-Carulla L, Martinez-Leal R, Salinas JA, Poole M, Martorell A, Novell R, Rueda P, Garcia-Ibañez J, Almenara J, Bas P. Análisis del impacto de plan estratégico sobre atención a los trastornos mentales y problemas de comportamiento en las personas con discapacidad intelectual. En Trastornos de la salud mental en las personas con discapacidad intelectual (Declaración FEAPS e Informe Técnico). Madrid: FEAPS, 2007, pp 15-112 ISBN: 978-84-693-1179-0.

Además de numerosas charlas a familiares, profesionales, cursos de formación, organización de congresos…

También a estancias en otros países para entender y mejorar las propuestas de atención. Cuatro meses con el profesor Nick Bouras y su equipo en el Guy's Hospital de Londres y otros cuatro meses en Boston en el Children's Hospital de Boston, adscrito a la Universidad de Harvard, con el Doctor Kerim Munir y el Doctor Ludwig Szymanski. (Ver ANEXO III, artículo *An international perspective of mental health services for people with intellectual disability*).

La UAVDI y el proyecto No + abuso.

Durante la realización del estudio y de las numerosas entrevistas a familiares y personas con discapacidad intelectual acerca de sus vivencias traumáticas, nos dimos cuenta tanto cuantitativa como cualitativamente de la situación de desprotección de las personas con discapacidad intelectual a ser víctimas de abusos y maltratos. Las relaciones de sumisión que establecen con personas sin discapacidad es la primera piedra. En estas relaciones de dependencia, todo lo que haga una persona sin discapacidad está bien y no debe ser cuestionado. Si a esto le añadimos que solemos infantilizar a las personas con discapacidad intelectual, vetándoles el acceso a cualquier conocimiento de cómo es una sexualidad sana, cuando una persona con discapacidad intelectual es víctima de una violación, en la mayoría de las ocasiones ni siquiera sabe que está mal.
La falta de interiorización de sus derechos, unido al desconocimiento del delito, hace que una PCDI no denuncie esta situación. Es más, el sistema judicial actual les es ajeno, careciendo incluso de los medios para poner una denuncia. Por ello, cuando lo dejan caer, de pronto, sin alarma, normalmente pasado un tiempo, dependen de terceros que se hagan eco de lo sucedido.

Estos terceros: profesionales de centros, familiares, médicos… son los que deben actuar. Pero normalmente, en un afán de protección, se decide no denunciar: no le van a creer, van a creer que lo ha buscado, lo va a vivir mal y va a sufrir… Con lo que estos tremendos delitos no ven la luz.

Si se superan todas estas barreras y se da la poca probable situación de que se decida denunciar, en los delitos de abuso sexual la prueba de cargo suele ser el testimonio de la víctima. Y aquí el testimonio, por estar contado de una manera diferente a la habitual, no suele considerarse con la suficiente fuerza y elaboración para procesar al agresor.

Esto deja a las PCDI en una situación de absoluta desprotección a ser víctimas de abuso sexual y al agresor impune: su víctima no lo cuenta, si lo cuenta no se denuncia y si se denuncia el testimonio de su víctima no es válido.

Al ser conscientes de esta tremenda situación, tuvimos que hacer otro parón y poner en marcha la primera unidad de atención a víctimas en nuestro país, de la mano de la Guardia Civil y gracias a la financiación de la Fundación Mapfre. (ANEXO IV).

10. Conclusiones

Con estos diferentes estudios hemos pretendido arrojar un poco de luz a la interrelación entre salud mental y discapacidad intelectual. No sólo son dos realidades que se entrelazan, sino que se encuentran desde lo más pequeño (el gen y el fenotipo conductual) hasta lo más amplio (los ojos con los que me mira el mundo).

De la mano del método científico hemos analizado el papel de los eventos vitales y los eventos traumáticos, ejemplificando el modelo de diátesis estrés que vertebra la aparición de la enfermedad mental. Con el método científico hemos analizado la relación de la enfermedad mental en las familias que tienen a su cargo una persona con discapacidad intelectual, ampliando así la visión de un modelo más biológico a uno más social, para acabar analizando cómo la enfermedad mental incide en variables macrosistémicas como el empleo.

Pequeños estudios que juntos han pretendido dar una visión, ya no tan científica sino cualitativa, del laberinto de interrelaciones de dos fenómenos tan complejos, pero que deben ser entendidos en toda su complejidad para abordarlos correctamente, porque al final, lo que buscamos, es entender qué apoyos necesitamos para que la calidad de vida (o felicidad) esté al alcance de todos.

Throughout all these studies, there is a connecting line which tries to shed some light to the interrelationship between mental health and intellectual disability. Two realities which encounter each other in the smallest (genes and behavioural phenotypes) and in the most immense (the eyes through which we are seen by the world).

Along with the scientific method, we have analysed the role of traumatic events and life events, exemplifying the diathesis-stress model. We have also analysed the relationship between mental illness and family impact when caregiving to a sibling with disability, broadening the scope and moving from a biological understanding to a more social one. And finally ending with a macrosystemic approach, which involves social and complex variables such as employment.

Little studies which built up together pretend to give a more intangible but broader scope: the infinite number of interrelationships which account for the higher prevalence of mental health problems in people with intellectual disability. But such a complexity has to be addressed and not overseen in order to identify optimal interventions, because, at the end, what we work for is for giving the most exact supports to improve quality of live (or happiness) for all.

11. Bibliografía

11. Bibliografía

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ANEXO I. Recurso DIEM.

Diem
centro de día

DIEM es una centro de día para personas con inteligencia límite o discapacidad intelectual ligera que presentan problemas de salud mental, en especial alteraciones de conducta.

Atendemos a un máximo de de 20 usuarios/as de entre 18 y 40 años que por su funcionamiento actual no puedan acceder a otros dispositivos de la Red de Discapacidad de la Comunidad de Madrid.

Perteneciente a la Fundación Carmen Pardo-Valcarce, DIEM está concertado con la Consejería de Familia y Asuntos Sociales de la Comunidad de Madrid.

Programa

Los usuarios/as acudirán al Centro en horario de 9:00 a 16:00. durante un período máximo de 2 años.

Desde el Centro realizamos distintas actividades con los usuarios/as, familiares y otros agentes de la comunidad implicados; como son:

- Coordinaciones presenciales y telefónicas con diferentes dispositivos de las redes sanitaria y de discapacidad,
- Sesiones terapéuticas individuales con el usuario/a,
- Sesiones familiares,
- Talleres y grupos terapéuticos,
- Atención urgente,
- Visitas domiciliarias (si la situación lo requiriese),
- Salidas grupales fuera del Centro, y
- Prácticas en el Centro Ocupacional Pardo-Valcarce.

¿Cómo trabajamos?

El objetivo principal de DIEM es el de promover la progresiva inclusión comunitaria de las personas atendidas tomando como base su historia y sus planes de futuro y desarrollando las mejores condiciones posibles de autonomía y calidad de vida.

La intervención procurará los siguientes objetivos específicos:

- Favorecer la recuperación y/o adquisición del conjunto de habilidades, capacidades personales y sociales necesarias para el funcionamiento en la comunidad.
- Prevenir el riesgo de descompensaciones reduciendo la sintomatología en el caso de que se hubieran producido.
- Proporcionar herramientas de evaluación e intervención a centros de atención directa con PCDI compartiendo las experiencias realizadas hasta el momento como modelo de funcionamiento.
- Ofrecer apoyo, asesoramiento y formación a las familias facilitando la adquisición de habilidades y competencias para mejorar la convivencia.
- Fomentar un ambiente laboral multidisciplinario, comunicador y bajo de estrés.

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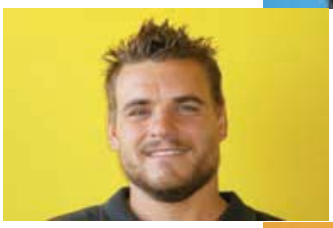

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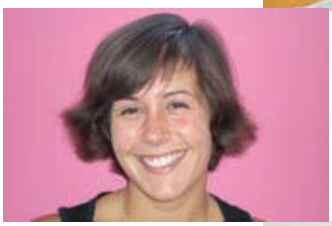

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La Suma de Todos
Dirección General de Servicios Sociales
CONSEJERÍA DE FAMILIA Y ASUNTOS SOCIALES
Comunidad de Madrid

CAJA MADRID

ANEXO II. Discapacidad intelectual y salud mental: Guía práctica.

Versión descargable en PDF:

http://sid.usal.es/libros/discapacidad/19210/8-12/discapacidad-intelectual-y-salud-mental-guia-practica.aspx

DISCAPACIDAD INTELECTUAL Y SALUD MENTAL

guía práctica

Fundación Carmen Pardo-Valcarce

CONSEJERIA DE FAMILIA Y ASUNTOS SOCIALES
Dirección General de Servicios Sociales
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ANEXO III. An international perspective of mental health services for people with intellectual disability.

The Maudsley Series

Mental Health Services for Adults with Intellectual Disability

Strategies and Solutions

Edited by Nick Bouras and Geraldine Holt

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CHAPTER THREE

An international perspective of mental health services for people with intellectual disability

Nancy Cain (USA), Philip Davidson (USA), Anton Dosen (The Netherlands), José Garcia-Ibañez (Spain), Virginia Giesow (USA), John Hillery (Ireland), Henry Kwok (Hong Kong), Almudena Martorell (Spain), Ramón Novell-Alsina (Spain), Luis Salvador-Carulla (Spain) and Jenny Torr (Australia)

INTRODUCTION

Internationally the trend in the direction of community integration has seen a move towards specialist community facilities and in-patient services for people with ID and mental health problems (Davidson and O'Hara 2007). The Mental Health in Learning Disabilities (MHiLD) Service and Estia Centre through their training, research and service development activities have collaborated with partners across several parts of the world to address the challenges that this brings to service providers. Some of our major partners have contributed to this chapter. They highlight the need to work in collaboration, to share knowledge and expertise and research ideas at a global level, to help shape and develop specialist mental health services for the benefit of all individuals with ID wherever they may be.

Although there is common ground within services in Europe, Australasia, the Americas and parts of Asia, there are marked differences in the development of services and where countries are in regard to achieving community-focused care. A comparison study between five European countries has shown that at an international level, there is considerable variation in quality and type of service provision for people with ID and mental health problems (Holt et al. 2000). Partly this is because of historical reasons to do with political and policy initiatives. In the USA the movement towards services built around people has grown out of the landmark Presidential Panel for people with ID in 1961 (whose initial report,

Combating Mental Retardation (Kennedy 1961) sought to include people with ID in everyday society). This philosophy of care was reiterated in 2004 through the New Freedom Initiative and the *Report to the President: A Charge We Have to Keep: A Road Map to Personal and Economic Freedom for Persons with Intellectual Disabilities* (President's Committee for People with Intellectual Disabilities 2004). How services are shaped is affected by competing paradigms; for example, within Australian policy, tensions are reported between the notions of how disability affects the individual and how society sees the individual and accommodates them, with the majority living in the community with family (Bigby and Ozanne 2001). Within Asia a survey of 14 countries found a wide variation of services; the type of service relating to wider economic and social considerations (Kwok and Chui 2008).

Disparity of service provision also exists between different regions of the same country where local pressures and resources have dictated service developments. Variation across continents and between services exists on a number of levels. These include:

- service design
- care packages
- funding streams
- commissioning
- staffing patterns
- resources.

These issues are further explored now with some of MHiLD and Estia Centre major collaborators from some other countries across the world.

REPUBLIC OF IRELAND

This interplay of national and local factors shaping a patchwork of service development even within one country is exemplified by the situation in the Republic of Ireland.

Historical context

Services for people with ID in Ireland developed from the mid-1800s onwards. Provided by Protestant philanthropists and Catholic religious orders, these were institutionally based and formed the structure on which current services are financed and delivered. People with ID also were placed in psychiatric hospitals. This was common until relatively recently. In recent decades much money has been set aside for resettlement of long-stay psychiatric patients who have no mental illness. In the 1960s schools and

community-based residential services were established by so-called 'parents and friends' groups. Such services became a template for the deinstitutionalisation and normalisation in the community of the more traditional campus-based services.

Services today

Today, with a few exceptions, services are community-based in whole or in part, with aspirations to close old campuses and move totally to the community. The medical services to the institutions were provided by doctors with psychiatric training. These doctors tended to have a wide remit beyond mental health issues including general health issues and epilepsy. The newer 'parents and friends' type model of development tends not to have psychiatrists in such positions. This has led to the current situation where many ID services have one or more psychiatrists while some have none at all. The psychiatrists usually treat people who attend the ID services and tend not to have a working relationship with the generic catchment area psychiatric services. If they are working with a multidisciplinary team, it is usually a generic ID team with no members, other than the psychiatrist, with specialist training in mental health and with no members designated to specialise in mental health issues. This has led to deficits in service provision (Royal College of Psychiatrists 2004). It can be very difficult for patients or, indeed, psychiatrists to access the resources needed for appropriate multimodal assessment and intervention.

The research and practical experience of the MHiLD Service and Estia Centre have informed services in a number of countries (Chapters 1, 5 and 8 of this volume), including recent activities and policy developments in Ireland. The policy document on mental health services produced in 2006 by an expert group appointed by the government, *A Vision for Change* (Department of Health and Children 2006) attempts to rectify the deficits in mental health services and gives special attention to the needs of people with ID. An asset to the planning process in Ireland is the availability of a resourced and regularly updated database of people with ID (the National Intellectual Disability Database, NIDD). This is maintained by the Health Research Board (www.hrb.ie). There are however no figures for the prevalence of mental illness in people with ID in the Republic of Ireland.

Using data from the NIDD, the expert group proposed recommendations for meeting the mental health needs of people with ID. These included promotion and maintenance of mental well-being as an integral part of service provision in ID services; catchment area-based specialist mental health of ID teams (two per 300,000 population for adults, one per 300,000 for children and adolescents); a spectrum of facilities to provide a flexible continuum of care based on need (five acute in-patient beds and 10 day

hospital places per 300,000 as well as rehabilitation and continuing care beds); and services to meet specific groups such as those with mild ID, those with autism and those in the 'forensic population'. The Health Service Executive – the national body responsible for planning and funding all publicly funded health services – has initiated a number of pilot projects based on these proposals.

The attitude to the mental health needs of people with ID has evolved greatly in the Republic of Ireland over the past 20 years, with concrete progress being made in the past few years. There is an obvious acknowledgment of the special needs of this group of the population. There are plans that form part of national policy which, if implemented, will make a great difference to the lives of people with ID and their families and carers. Unfortunately, the current downturn in the world and national economy may jeopardise the implementation of these plans and policies.

THE NETHERLANDS

Historical context

In the Netherlands the differentiation between mental illness and ID dates from the second half of the nineteenth century. However, until the 1950s, institutions for housing people with ID were a rarity. Most individuals with ID were living in family homes or were placed in psychiatric hospitals. In the 1960s, the ideology of 'normalisation' influenced policy for community care. Developmental and educational models of care prevailed for people with ID. Psychiatrists distanced themselves from the care of people with ID while psychology, pedagogy, social work and nursing took the lead. There was little interest in or recognition of the mental health needs of this population.

With the implementation of deinstitutionalisation in the 1970s and 1980s, behavioural and mental health problems became visible. Initially, social care models were used by the non-psychiatric professionals, but the severity of the problems prompted them to request the input of psychiatrists. In this way, during the 1980s, many people with ID made their re-entry into psychiatry. The dilemma was whether to provide generic or specialised mental health services as in other western countries (Bouras and Holt 2001).

In the early 1980s, special clinical centres for adults with ID and severe behaviour disorders were established. Five centres accommodating some 150 in-patients in five country districts were set up, each centre serving an area of three million inhabitants. These centres cater for people with an IQ of 50–90. This broad eligibility criterion is different to other international

models, many of which have an upper cut-off at IQ 70. Patients are treated for up to three years and, after treatment, returned to their former milieu. No facilities of this sort were made available for people with moderate and more severe ID. However, a number of centres had already been set up for the observation and treatment of children and adolescents with mild ID and behavioural problems.

The positive effects of these centres became visible within a relatively short period of time. People with severe and chronic psychiatric and behavioural problems, who were not served adequately by general psychiatry, could be assessed and treated properly in these centres. Specialist knowledge within multidisciplinary teams and research increased among young psychiatrists and other professionals for this population.

However, soon it became apparent that these centres were only a temporary solution for a larger problem. The centres provided exclusively in-patient treatment, waiting lists for admission became too long, aftercare was not well organised, and people with moderate and severe ID were excluded.

Services today

At the beginning of the 1990s some in-patient centres developed community outreach multi-professional teams to provide mental health interventions within the living milieu of people with ID. A few general psychiatric hospitals started specialised departments for the assessment and treatment of people with ID. In parallel a professorship in the psychiatric aspects of ID at the Radboud University in Nijmegen was established, which together with the European Association for Mental Health in ID, based in the Netherlands, advocated for specialised services for those with mental health problems and ID.

Some structural changes were implemented in the early 2000s to bring specialist services for people with ID closer to generic mental heath services. These changes enhanced further staff training possibilities, and the number of psychiatrists working in this field of ID has significantly increased (Dosen 2005). Training for psychologists, pedagogues, social workers and nurses has also been improved.

Recent service developments have contributed to breaking down some historical barriers in this field. The most severe barrier was ignorance about the special needs of this population with respect to their mental health, and of the need for specialist knowledge concerning psychiatric diagnostics and treatment of these people (Bouras et al. 1993). One of the barriers was a gap between the two care systems, one for those with ID and another system for mental health care for the general population. Participation of professionals from one system in the other, sharing of professional knowledge and

cooperation in care provision offer a solid base for the future development of a real and all-embracing mental health care system for this population.

SPAIN

Historical context

The interest in the mental health of those with ID started early in Spain. In 1969 a group of clinical experts including adult psychiatrists, child psychiatrists, psychologists and stakeholders founded the Spanish Association of Scientific Research in Mental Retardation.

This association was quite influential and was supported by other key organisations in the field such as the Spanish Federation of Family Associations of People with ID. Unfortunately this development came to a halt in the late 1970s because of the relatively low interest of the health care sector including psychiatric services in ID, the increasing interest of clinicians in other areas of psychiatry such as ageing and child psychiatry, and the progressive shift of ID care from the health sector into social and education sectors. This shift increased in the mid-1980s with deinstitutionalisation. The 1986 Health Act included mental health as an area of importance but it did not mention ID, as it was considered mainly a social problem and was excluded from the health care system and from the academic curriculum in medicine and clinical psychology.

During the 1980s, the education sector integrated children with ID into mainstream schools, and the national social care agency together with regional and local NGOs developed a successful network of residential, training and employment programmes. By the 1990s many people with ID had been moved from psychiatric institutions into the community and to residential facilities under the social care sector. By then, stakeholders, families and family associations realised that there was a significant proportion of people with ID who needed psychiatric care.

In the early 1990s only a few psychiatrists were actively involved in the care of people with ID in Spain. They were in the public health system, NGOs, institutional care, and the social care system. However, there was lack of knowledge and skills in diagnostic and treatment methods and specialist training.

In 1989, Dr Juan Perez-Marín, president of one of the main NGOs providing care for people with ID in Spain, invited Professor Luis Salvador-Carulla (University of Cadiz) to assist with service developments for people with ID and mental health problems in Andalucía. A long-lasting collaboration started with MHiLD service and Estia Centre for service developments, training and evaluative research in Spain (Salvador-Carulla and Martínez-Maroto 1993).

Services today

Although there are large regional differences, specialised services for people with ID and mental health problems are being implemented all over Spain (Salvador-Carulla and Maroto 1993; Holt et al. 2000; IDRESNET 2003; Salvador-Carulla et al. 2007). Experts, health authorities, family organisations and professional associations are working together to meet the needs of this population.

For the first time, the needs of people with ID and mental health problems were included in the Catalan Mental Health Plan (2006–2010) (Departament de Salut 2006). The service model was inspired by the MHiLD model (Chaplin et al. 2008) and included a number of specialist mental health components, outpatient centres coordinated with the general mental health system as well as four sub-acute mental health hospital units in the four provinces of Catalonia. The system also incorporated community residential care and coordination with the social care sector.

In 2007, the two main organisations for the care of people with ID produced a plan to develop services for those with ID and mental health problems in Spain. This plan selected the care system in Catalonia as a benchmark and adapted it to the 17 Autonomous Regions in Spain (Salvador-Carulla et al. 2007) and it has been considered by other Autonomous Communities such as Extremadura, Castilla y Leon, Castilla La Mancha, Canary Islands, and Galicia. In the meantime, in Madrid two residential centres for sub-acute care, a day centre and a specialised outpatient community centre have opened.

AUSTRALIA

Historical context

Australia is a federation of six states, two major mainland territories and other minor territories, covering a land base of 7,686,850 km^2 with a population of 21 million. The state and territory governments are responsible for the provision of free public hospital and related community health services including mental health services. Private fee for service medical and certain other health services are subsidised by Medicare, a federal universal health insurance scheme. Private health insurance offsets the cost of private hospital stays.

Historically, institutional care of people with ID was the responsibility of state health departments. The shift from institutional to community care of people with ID split the provision of health services from social services. In general, state disability services are responsible for accommodation and occupational services while health and mental health needs are assumed by policy-makers to be met by generic health and mental health services,

although the configuration and organisation of both disability and health services vary from state to state.

Generic public mental health services have failed to meet the mental health needs of Australians with ID (Parmenter 1988; Moloney 1993; Einfeld 1997). The Human Rights and Equal Opportunity Commission concluded that there was 'an urgent need for academic research, increased clinical expertise and substantial increased resources' (Burdekin 1993). The needs of people with ID and mental health problems have been acknowledged in key national policy documents over the past decade. The Second National Mental Health Plan (Australian Health Ministers 1998) identified people with ID as one of the target groups with high-level needs and called for improved treatment and care, improved access to and response by services; however this was to be achieved using existing resources. An evaluation of the Second National Mental Health Plan (Steering Committee for the Evaluation of the Second National Mental Health Plan 1998–2003 2003) concluded that the development and implementation of effective mental health service models for people with ID had not been realised and needed to be afforded higher priority. The National Mental Health Plan 2003–2008 (Australian Health Ministers 2003) calls for better coordination of existing services for people with complex needs but makes no mention of the need for specialist expertise or clinical services.

Services today

There are few specialist mental health services for people with ID in Australia. These are limited in scope, such as consultation-only services, or tend to be *ad hoc* initiatives of psychiatrists with an interest in ID, or are provided by academic units in developmental disability health (Centre for Developmental Disability Health Victoria (CDDHV), Monash University; Queensland Centre for Intellectual and Developmental Disability (QCIDD), University of Queensland), rather than being driven by coherent policy.

This policy failure is reflected in a series of surveys of Australian psychiatrists over the past decade (Lennox and Chaplin 1996; Edwards et al. 2007; Jess et al. 2008; Torr et al. 2008). The findings are similar across states and over time. Psychiatrists in Australia agree that adults with ID receive a poor standard of care in both in-patient and community mental health settings, that antipsychotics are over-prescribed and that a higher standard of care would be provided by specialist services if they existed. Psychiatrists are also concerned about the interface between mental health and disability services and the training and support of direct support workers.

Australian psychiatrists and trainees report that they are not well trained in the assessment and management of mental health and behaviour problems in people with ID, they tend not to make specific diagnoses and many

would prefer not to work with people with ID (Lennox and Chaplin 1995; Lennox and Chaplin 1996; Edwards et al. 2007; Jess et al. 2008; Torr et al. 2008). The Royal Australian and New Zealand College of Psychiatrists has no mandatory training requirements in ID (Royal Australian and New Zealand College of Psychiatrists 2003). The development of clinical expertise is limited by the small numbers of people seen with ID and limited opportunities for specialist clinical training.

There is, though, cause for optimism that there will be improvements in specialist mental health service provision to people with ID in Australia as well as new opportunities for training. Victoria, New South Wales (NSW) and Queensland have quite different initiatives to address mental health needs of people with ID.

In Victoria, a state-wide mental health in ID service has provided consultation and training to state-run area mental health services (AMHS) over the past decade (Bennett 2000) and provides one training position for a psychiatry registrar. There are limitations to this service in that a person with ID must first access the AMHS. AMHS limits services to serious mental illness such as psychoses and high-risk mood disorders, and these disorders may not be recognised in a referred person with ID. A Victorian government green paper on mental health reform includes a section asking how mental health services for people with ID can be improved (Victorian Government Department of Human Services 2008).

In 2007 the NSW government funded the first Chair in Disability Mental Health in Australia. The position was established to increase workforce capacity to deliver appropriate and effective mental health services to people with ID as well as establishing research into mental health and ID. This will build on the existing hospital clinics operated by psychiatrists with long-term interest in ID.

Queensland has maintained a 31-bed facility for people with ID and mental disorders who require extended in-patient care and rehabilitation, which is to the author's knowledge the only specialist in-patient facility for people with ID in Australia. In 2007 the Carter Report on the plight of people with ID and violent challenging behaviour was tabled in the Queensland Parliament. In response the Queensland government has pledged substantial resources for specialist behavioural support services integrating disability and mental health services. Teams will include a range of professionals including psychologists, occupational therapists, speech and language pathologists, psychiatric nurses, neuropsychologists, psychiatrists and general practitioners. A centre of excellence will provide an academic and research base.

With the exception of South Australia, the remaining states and territories have no initiatives to address specifically the mental health needs of people with ID. South Australia has recently funded a full-time psychiatrist

position in ID psychiatry, but as yet does not have a specialist mental health service for people with ID.

Over the past decade the CDDHV, Monash University and the QCIDD, University of Queensland have developed close links with MHiLD service and Estia Centre. Both centres aim to improve the health and well-being of adults with intellectual and developmental disability through the provision of clinical services, professional education and research. Collaboration with CDDHV developed online learning programmes in the psychiatry of intellectual and developmental disability for psychiatry registrars. Collaboration with QCIDD led to the development of a mental health training package for Australian support workers of those with ID (Edwards et al. 2003).

HONG KONG

Historical context

Hong Kong covers an area of about 1000 km^2 and has a current population of about 6.8 million (Census & Statistical Department 2007). The history of psychiatry in Hong Kong started in 1875 when the first asylum was opened (Lo 2003). In the subsequent 100 years, psychiatry was gradually modernised with the opening of new psychiatric facilities, training of more qualified psychiatric personnel and the development of subspecialties. The earliest sign of developing a specialised medical service for people with ID appeared in 1972 with the opening of the Siu Lam Subnormal Hospital, an institution with 300 beds that provided infirmary services to adults with severe and profound ID. Apart from this small group, all other people with ID and mental illness or behavioural disorders were covered under Hong Kong's generic mental health service.

With the promotion of the concept of normalisation (Nirje 1972; Wolfensberger 1972) and backed by the burgeoning economy of Hong Kong in the second half of the twentieth century, the Social Welfare Department and NGOs started to open community services for adults with ID. These included group homes, hostels, sheltered workshops and day activity centres. The increasing presence of people with ID, together with the input from the parents' groups, succeeded in convincing some health care managers and administrators to put more emphasis on ID services.

In 1994, the Siu Lam Outreach Service was commenced, with the primary objective of assessing the eligibility and suitability of people with ID who were applying for their infirmary service. At the same time, the team started to provide psychiatric care and support for other people in community ID facilities.

A breakthrough occurred in the following year (1995) when one of the two mental hospitals – Kwai Chung Hospital (KCH) – decided to develop

a new specialist psychiatric service for adults with ID. At that time, KCH consisted of a total of 1622 psychiatric beds distributed over 34 wards and there were four psychiatric outpatient clinics located within its catchment area. Altogether, the in-patient and outpatient facilities provided mental health services for about one-quarter of the total population of Hong Kong. A hospital survey conducted in that year found that about 10% of the in-patient population were patients with ID and mental illness or behavioural disorder (Kwok 2001). It was acknowledged that specialised skills and knowledge were required to care for this population who constituted a significant proportion of those 'difficult to discharge'. Setting up a specialist team for ID was part of the process of deinstitutionalisation and was intended to help reduce the total number of in-patients of the mental hospital.

Services today

As a result, the first psychiatric unit for ID in Hong Kong was formally opened in Kwai Chung Hospital in 1996. It was headed by a specialist ID psychiatrist who had worked previously at MHiLD service and Estia Centre to acquire specialist knowledge and clinical skills for assessing and treating psychiatric problems in people with ID. The mission of this specialist unit was to meet the mental health needs of people with ID by providing a high-quality, coordinated and comprehensive psychiatric service that incorporated the principles of normalisation and community integration.

The in-patient service consists of one male and one female ward, each with 40 beds. This service is supported by multidisciplinary staff and provides an appropriate environment for specialist assessment and treatment for people whose mental health needs cannot be met in the community. Close links with families and community carers are maintained, with much emphasis on transfer of intervention skills so as to facilitate early and successful discharge of patients. Outpatient service carries an equally important weighting as the clinic is serving a catchment population of about 1.5 million. In addition, intervention may also be in the form of outreach services. By seeing patients in hostels, group homes, day centres or sheltered workshops, the team can work closely with other professional carers and family members to ensure that practical advice can be delivered directly and treatment programmes (e.g. behavioural modification) successfully implemented.

In subsequent years the unit has grown significantly, with further increases in service elements and the creation of specific programmes to meet the needs of people with ID. It has been accredited by the Royal College of Psychiatrists as a training centre on the psychiatry of ID. It has also become a model for another mental hospital (Castle Peak Hospital) to

set up its own specialist service in another region of Hong Kong. The unit maintains close collaboration with the MHiLD service and Estia Centre, and continues to benefit from their support in the form of academic programmes and clinical attachments for its multidisciplinary trainees.

THE ROCHESTER MODEL (USA)

Historical context

In 1989, reports first appeared of a model community-based service to stabilise behavioural or psychiatric episodes occurring in people with ID that threatened to limit or curtail their options for remaining independent (Davidson et al. 1989, 1995; Davidson & O'Hara 2007). The model linked a tertiary specialised psychiatric in- patient unit to effect stabilisation with both specialised and generic behavioural and psychiatric clinics, to provide ongoing community-based follow-up and medium- or long-term treatment. One key feature of the model was its comprehensiveness. Another feature was that its funding was derived largely from grants, rather than fees for service. Unlike the programmes in the UK that were a part of the overall health system, the model was too costly to maintain as an integrated component of a larger mental health delivery system funded from insurance resources (Davidson et al. 1995). It was felt that components such as the community-based crisis intervention team might remain viable because of their relatively high throughput and comparatively low cost. But components that assured availability of in-patient options for initial crisis stabilisation and access to ongoing follow-up care would not be sustainable.

Between 1989 and 2000, myriad changes occurred in the array of community-based options available to people with ID. In the US, there was a nationwide effort to depopulate aggregate residential care in favour of small-group or individual community-based residential options. This systemic change was mandated by legislative and regulatory changes limiting expenditures of federal funds for aggregate care (Braddock et al. 2008). Simultaneously, health (and therefore mental health) care financing was moving from a fee-for-service based system to one that was increasingly dominated by managed care options (Birenbaum 1999). These two strategic changes created acute and persistent barriers to providing adequate services and supports to people with ID and concomitant mental health and behavioural problems. While managed care plan managers were limiting options for extended and comprehensive community-based mental health services, people with ID and mental health problems required these very services to enable them to leave aggregate care for less restrictive residential and work options in the community.

Meanwhile, the predictions referred to above came true. The Rochester model lost key components that would have prevented some of the barriers created by the conflict between managed care and full inclusion of people with ID. Grant funding of specialised in-patient mental health services ended, followed quickly by the elimination of the specialty services themselves, which could not survive the lack of funding from managed care. But enough of a residual legacy was left in place in several local tertiary inpatient units to support 'specialised' care within the generic system. ID community agencies that relied on long-term behavioural services and consultations from the crisis intervention team acted to increase their indigenous capacity to provide such services under their own comprehensive care systems. The overall cost to any one agency was minimised by the near universality across local provider agencies to establish their own response capacity. So in an unanticipated sequence of events, the system reinvented itself.

Some of these outcomes would not have occurred if the original Rochester Model had not been based in a regional university medical centre. This component of the model afforded access to both pre-service and continuing professional education programmes that, in turn, made specialised training available to health and mental health students and professionals representing key disciplines needed to staff community-based specialty programmes. Many of these trainees went on to become leaders in the local community and to exercise entrepreneurial influence on the development of new service options within the generic health, mental health and ID systems. Several collaborated on research (including colleagues at MHiLD service and Estia Centre) that led to publications in the scientific literature. There was also a shift in the training culture within the medical centre towards a positive view of the need to develop skill sets for providing services and supports to people with ID and mental health problems which sustained components of the medical school and nursing school curricula to address diagnosis and treatment services for this group. The students welcomed this, since they were aware that people with ID now lived and worked in the communities where they would be practising and that their caseloads would include people with ID and mental health problems.

Services today

The system continues to change and there are potential threats. For instance, the increase in diagnosis of autism spectrum disorders coupled with the necessity for providing community-based services for both children of school age and adults of working age is already making demands on the service system that may be difficult to address. Secondly, the greying of the general population is mirrored in survival trends among people with ID

(Janicki et al. 1999). There are suggestions that these trends may be accompanied by shifts in mental health status (Cain et al. 2003; Davidson et al. 2003; Janicki et al. 2002; Stawski et al. 2006) but the details of the impact are not yet clear. Changes in skill set training needs, treatment modalities and shifts in residential service options will become increasingly important as these cohorts age. However, in Rochester a *bona fide* community network has been created with a sustainable future. Only unanticipated changes in funding are likely to disrupt this apparently optimistic future.

CONCLUSION

The collaboration between the MHiLD service and Estia Centre and colleagues in the UK and farther afield, as illustrated above, has had mutual benefits. Many of the issues faced in providing mental health services to people with ID have been universal, for example the move towards social care in the community resulted in a loss of mental health provision for this client group, and many mental health workers and direct care staff lacked knowledge and skills in working with those with ID and mental health problems. The efforts, often of a few key people, supported by the voices of clients and their families enabled a sharing of skills and experience through consultation, visits, teaching activities, research and clinical initiatives.

People with ID, especially those with mental health problems, tend to be marginalised. Such collaborations, sometimes informal and at other times formalised through organisations such as the European Association for People with Mental Health Problem and ID and the ID Section of the World Psychiatric Association, support clinicians and others to advocate for this client group's need for appropriate services.

Several countries around the world are trying to address the mental health needs of their population with ID. Unfortunately there is a paucity of information from the developing world. Currently efforts are being made to encourage similar developments by promoting professional collaborations and supporting relevant publications (Jeevanandam 2009; Njenga 2009; Mercadante and Paula, 2009 in press).

NECESSARY STEPS TO BETTER SERVICES

There is an International consensus from the existing data that mental health services for people with ID and mental health problems should include:

- some form of service specialisation
- community outreach and in-patient facilities
- strong links with both general mental health and ID services

- provided by the health care sector
- collaboration between health and social care sectors
- specialist training.

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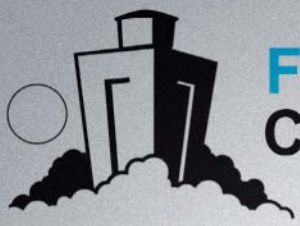
ANEXO IV. Recurso UAVDI.



Fundación
Carmen Pardo-Valcarce

UNIDAD DE ATENCIÓN A VÍCTIMAS CON DISCAPACIDAD INTELECTUAL

FUNDACIÓNMAPFRE

¿CUÁLES SON NUESTROS OBJETIVOS?

1. Responder a la situación de vulnerabilidad de las víctimas de abuso sexual con discapacidad intelectual, ofreciendo un servicio de ayuda integral en todo el proceso judicial y psicológico y adaptando las herramientas forenses y terapéuticas pertinentes.

2. Ofrecer a los cuerpos de seguridad el asesoramiento en la metodología a seguir en las entrevistas policiales a las víctimas con discapacidad intelectual.

3. Validar un instrumento de evaluación de capacidades y de análisis del testimonio para los casos de sospecha de abuso sexual a personas con discapacidad intelectual.

4. Intervenir a través del trabajo en red, de evaluación y terapéutico en aquellos casos derivados por profesionales de otros servicios (centros ocupacionales, juzgados, centros de salud, etc), ofreciendo terapia psicológica y educación sexual a las víctimas y sus familias.

5. Trabajar en la prevención del abuso sexual a personas con discapacidad intelectual.

¿POR QUÉ NACE LA UAVDI?

Las personas con discapacidad intelectual son especialmente vulnerables a sufrir diferentes tipos de abuso. Cada vez hay más estudios que nos alertan del elevadísimo número de casos de abusos sexuales perpetuados a personas con discapacidad intelectual, que sólo en los últimos años han empezado a ser denunciados en nuestro país.

Entre las causas señaladas para los elevados datos que tenemos de prevalencia del abuso sexual en personas con discapacidad intelectual se encuentran las menores habilidades de comunicación para relatar lo ocurrido, las relaciones de sumisión a las que tanto están acostumbrados, el desconocimiento de que lo que está sucediendo no es correcto o la falta de credibilidad dada a su testimonio.

Debido a esta situación de desamparo, siendo conscientes de la inexistencia de un servicio de ayuda especializado a víctimas con discapacidad intelectual y tras una demanda de colaboración por parte del cuerpo de la Guardia Civil, nace nuestro Proyecto de "Detección, Intervención y Criterios de Veracidad en Abusos de Carácter Sexual en Personas con Discapacidad Intelectual" y la Unidad de Atención a Víctimas con Discapacidad Intelectual (UAVDI), de la Fundación Carmen Pardo-Valcarce, gracias a la financiación de la Fundación MAPFRE.

¿CÓMO TRABAJAMOS?

Nuestro proyecto tiene tres ejes principales de actuación, a partir de los cuales hemos desarrollado diferentes programas u actividades:

INTERVENIR	INVESTIGAR	PREVENIR
• Asesorando a los profesionales, familiares o personas cercanas a una posible víctima de abuso sexual, sobre los pasos a seguir. • Realizando una evaluación forense con todas las garantías. • Ofreciendo terapia psicológica y educación sexual gratuita a la víctima y su familia.	• En Métodos de Entrevista Forense a Personas con DI. • En Evaluación de Capacidades a Personas con DI. • En Identificación de Personas y DI. • En Análisis de la Credibilidad del Testimonio aplicado a DI. • En Terapia Psicológica a Víctimas de ASDI.	• Con jornadas de difusión del proyecto. • Acompañando a la Guardia Civil a partir de las denuncias. • Con programas de sensibilización. • Con cursos de formación a profesionales y cuerpos de seguridad. • Con el desarrollo de la "Guía de Intervención en casos de AS a personas con DI".

¿QUIÉNES SOMOS?

En la Unidad de Atención a Víctimas con Discapacidad Intelectual trabajamos un grupo de psicólogos especializados en el trabajo clínico con personas con DI, un equipo de psicólogos forenses y el equipo de investigadores y profesionales de la Fundación Carmen Pardo-Valcarce.

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Art.16.2 "Los estados Partes adoptarán todas las medidas pertinentes para impedir cualquier forma de explotación, violencia y abuso asegurando, entre otras cosas, que existan formas adecuadas de asistencia y apoyo que tengan en cuenta el género y la edad para las personas con discapacidad y sus familiares y cuidadores, incluso proporcionando información y educación sobre la manera de prevenir, reconocer y denunciar los casos de explotación, violencia y abuso…"

Art.16.4 "Los Estados partes tomarán todas las medidas pertinentes para promover la recuperación física, cognitiva y psicológica…de las personas con discapacidad que sean víctimas de cualquier forma de explotación, violencia o abuso…"

Convención de Naciones Unidas sobre los Derechos de las Personas con Discapacidad (ratificado por España en 2007)

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